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Living with dementia in small-scale and traditional long-term care settings

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Living with dementia in small-scale and traditional long-term care settings

A longitudinal comparative study on residents,
family and professional caregivers in the
Netherlands and Belgium

Ietje de Werd-de Rooij

Colofon

The studies presented in this thesis were conducted at Tranzo, Tilburg University, in cooperation with De Wever, Tilburg.

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Voor mijn pleegmoeder tante Jeanne († 1978)

Op het moeilijkste kruispunt van mijn leven liet je mij de verschillende wegen en paden zien en steunde me in het kiezen voor de juiste weg.

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*Yesterday is history,
Tomorrow is a mystery,
And today?
Today is a gift,
That is why we call it the present!*

(Christmas wish from Mom Rose, age 92, December 2011)



General introduction

CHAPTER 1

Background

Worldwide, the number of people with dementia is increasing [1]. Dementia is a complex disease which manifests itself in various forms and is characterized by an initially gradual and progressively deteriorating impairment of brain functions. It is a multifaceted disorder, affecting respectively cognition, mood, personality, behavior and the ability to perform activities of daily living [2, 3]. Although a large number of people with dementia receives care at home, in the later stages of dementia the need for care often increases [4], making the move to a long-term residential care setting inevitable [5]. Therefore, the expected substantial increase in the number of people with dementia will place a greater demand on residential care [6].

At the same time, the medical- and nursing based approach in dementia care in traditional residential care settings has been criticized for being too hospital-like and not person-centred enough [7]. In reaction, many large nursing homes are transforming their traditional care facilities to home-like, holistic and more person-centered ones. Often newly developed care settings also adhere to this new vision [8]. Small-scale living for older persons with dementia is a relatively new form of long-term care designed to bring about the envisaged transformation towards more home-like, holistic, and person-centred dementia care [8-10]. Although currently, a widely accepted conceptual definition for small-scale living does not exist, there are some common characteristics [8, 11, 12] (see Table 1).

Table 1. Characteristics of typical small-scale and traditional long-term care settings [8, 13, 14]

Small-scale long-term care settings	Traditional long-term care settings
Home-like, holistic and person-centred approach	Medical- and nursing based approach
Focus on the normalization of living and maintenance of one's original lifestyle	Focus on care
Additional focus on client interaction	Main focus on basic technical care giving skills
Participation in daily activities is stimulated	Staff performs most daily activities
Groups are relatively small (usually 6 – 8)	Groups are larger (usually >20)
Day schedule according to resident's preferences	Routine institution directed day schedule
Environment is familiar and home-like	Environment is hospital-like
Number of caregivers is smaller	Number of caregivers is larger
Staff wears no uniforms	Staff wears uniforms
Staff tasks are integrated	Staff tasks are more differentiated
More individual decision making by staff members	More collective decision making by staff members

Over the last decade, the number of small-scale living facilities for people with dementia has been increasing in countries all over the world, such as Sweden, Japan, the United States, the Netherlands and Belgium. The appearance of these facilities, however, differs between countries [12]. In Sweden, the first small-scale living settings were called 'Group-Living' settings, designed for five to nine residents with mild to moderate forms of dementia, which eventually developed into homes for life [15]. In Japan, 'Group Homes' are usually attached to a larger facility or self-containing residences, also with five to nine residents. Residents are encouraged to engage in daily housekeeping if possible [16]. In the United States the first example of small-

scale living settings were so-called ‘Greenhouses’, which are small self-contained houses for ten or fewer older persons taken care of by professional caregivers being ‘universal workers’ with integrated tasks such as cooking meals and providing personal care [10]. In the Netherlands and Belgium ‘small-scale living’ or ‘group living’ facilities usually provide housing and care to about six to eight residents with an emphasis on normalized living in an environment that is as familiar and home-like as possible [12]. Belgium has a relatively longer history (since 1978) [17] than the Netherlands (since 1986) [18] of providing small-scale long-term residential care for people with dementia, however in the Netherlands the pace of the development of small-scale facilities after start has been faster [19].

Although already many small-scale living facilities have been created and organizations providing care for older people have endorsed the vision related to small scale living and care [17, 20–22], the concrete evidence for an overall beneficial effect of living in small-scale facilities for older people with dementia is scarce [8, 13, 23]. Up until now, studies that compare traditional and small-scale living settings have established only a few and rather slight differences in outcomes between residents. A recent study in the Netherlands, for example, found no differences in the average depression scores of residents in small-scale living and traditional long-term care settings [23]. Furthermore, previous research has shown that after relocating older residents with dementia to small-scale living facilities, behavioural problems temporarily increased, but that this effect disappeared after a year [24]. Also, more recent Dutch studies were unable to detect lasting effects of small-scale living on behavioural problems [13, 23]. In addition, residents living in small-scale facilities reveal the same quality of life on the domains positive affect, self-image, and feeling at home compared to residents living in traditional settings [13, 23].

Nevertheless, differences that have been found were mostly in favour of small-scale living settings. For example, residents living in small-scale care facilities appear to be more frequently engaged in verbal communication [25], show more interest in their surroundings [3], have better relationships with others in the nursing home [8], and generally seem to be more socially engaged compared to residents living in traditional settings [13]. Moreover, they have been reported to have better emotional health compared to residents in traditional nursing home care [8]. Both the prescription of psychotropic medication and use of restraints have been found to be employed less frequently in small-scale settings [13, 23].

Despite these findings, the overall beneficial effects of living in a small-scale facility compared to living in a traditional facility for people suffering from dementia have been inconclusive.

Furthermore, as others have acknowledged as well, next to the perspective of residents, the perspective of family caregivers [14, 26, 27] also matters. The family system implies an important part, possibly the most important part of the social environment of older persons with dementia [26]. Taking care of a relative with dementia, in general may provide family with satisfaction [28, 29], but it can also be burdensome [30].

In addition, the perspective of professional caregivers also deserves more attention [14, 31]. Differences in the way of care giving between small-scale and traditional living facilities, could also have implications for the pressure of work and work satisfaction experienced by professional caregivers. In general, nursing is considered to be a challenging job and can be experienced as stressful [32]. Moreover, higher levels of stress [33] as well as increased impairments in the patient’s ability to communicate [34] influence the risk of burnout and carer’s mental health problems. Therefore it is important to examine whether the differences in underlying vision and execution of care between small-scale and traditional settings also might have implications for both the target groups of family as well as professional caregivers.

Aim and research questions

To contribute to existing knowledge, the aim of this thesis is to compare small-scale and traditional long-term care facilities for residents with dementia more integrally, incorporating different aspects of the perspectives of respectively residents, family caregivers and professional caregivers. Moreover, complementary to previous studies on small-scale living, the sub-studies, being part of the overall study for this thesis, also try to compare outcome patterns between the Netherlands and Belgium.

The central research question in this thesis is: What are the differences and similarities between small-scale and traditional long-term care settings in the Netherlands and Belgium, from the perspectives of the residents with dementia, the family, and the professional caregivers?

The specific research questions addressed in this thesis are:

- (1) Which (combination of) changes in elements affect (different dimensions of) the quality of life of elderly residents with dementia in long-term care settings over the course of one year?
- (2) What are the benefits of traditional and small-scale living facilities on the quality of life of residents with dementia within the Netherlands and Belgium?
- (3) How do residents with dementia living in small-scale and traditional long-term care settings in the Netherlands and Belgium differ in terms of activities of daily living, behavioural problems, depression, use of restraints, psychotropic medication, social engagement and visiting frequency of relatives.
- (4) What is the family caregiver perspective in traditional versus small-scale long-term care settings in the Netherlands and Belgium on:
 1. the interaction between family caregiver and resident?
 2. the interaction between professional caregiver and resident?
 3. the interaction between family caregiver and professional caregiver?
- (5) Are there differences in work-related mental health problems and burnout for professional caregivers working in traditional versus small-scale long-term care settings for elderly people with dementia in the Netherlands and Belgium?

Study design

To answer these research questions three longitudinal comparative sub-studies were conducted in residents, family and professional caregivers in small-scale and traditional long-term care settings in the Netherlands and Belgium. All three studies were conducted over the course of one year, however the study on residents had three measurement moments (baseline, after six, and twelve months), whereas the studies on family and professional caregivers had two measurement moments (baseline and after twelve months).

Setting the scene

The research project discussed in this thesis was conducted in two countries to provide a broader view of the researched issues in dementia care. Dementia care in the Netherlands and Belgium is comparable, because both countries are welfare states providing long-term care services for mostly everyone in need of chronic care. In both countries the same type of disease prevalence can be seen, being comparable to the appearance worldwide [1]. For the Netherlands, the expectation is that in 2030 there will be 319,312 people with dementia, an increase of 65% over a period of 25 years [35]. In Belgium, the burden of dementia on health care is also considerable [36]. The expectation for this country is that there will be 251,000 people aged over 65 with dementia in 2030, a rise of 56% over 25 years [37]. Moreover, comparable types of small-scale and traditional living, with similar visions on care for older people with dementia, exist in both countries.

However, there are some differences as well. In the Netherlands, long-term care settings are mostly non-profit foundations. Funding is nowadays based on a system of Care Severity Packages (Zorgzwaartepakket / ZZZP) provided by the government on behalf of the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten / AWBZ), which funds long-term care facilities (care homes) to provide care for individual residents [38]. In addition, residents are obliged to make an income-dependent contribution [39]. The actual admission to a long-term care facility in the Netherlands is determined by a governmentally regulated standard assessment procedure performed by an independent care indication office (Centrum Indicatiestelling Zorg / CIZ), leading to an objective care indication, taking into account the resident's future needs, as well as the resident's or legal guardian's preferences. About 25% of Dutch long-term institutional dementia care settings nowadays involve small-scale facilities; each facility providing care to six to eight residents [23]. Unique for the Netherlands is that nursing home medicine in the Netherlands has become a specific medical discipline [39].

In Belgium institutional long-term care settings are stand-alone, private non-profit entities. These settings are partly funded by the federal government, and partly by the regional authorities. Additionally, residents have to pay a daily fee for food and lodging. Admission into a nursing home is not regulated by the government, although nursing homes receive higher funding from the government for residents with more care needs, discouraging them from admitting independent people [40]. Groups in small-scale living facilities in Belgium are often larger (extended to 12 to 15 residents) than groups in the Netherlands due to funding issues [17]. Compared to the Netherlands, nursing staff more often consists of higher educated and certified nurses instead of nursing assistants.

The studies in this thesis took place in five different nursing home organizations in the south of the Netherlands (Noord-Brabant) and Belgium (Flanders). These care settings incorporated four traditional and twelve small-scale facilities and had pre-existing collaboration arrangements within the academic networks of Tilburg University and K.U. Leuven.

Residents

The main focus of this thesis is on *residents in small-scale and traditional long-term care settings*. First, to be able to answer the research questions (2), concerning quality of life of older residents with dementia, and (3), concerning functional status, behaviour and social interaction of older residents with dementia, a literature review was conducted to establish the relevant factors influencing the outcome of care of older residents with dementia. The literature revealed that quality of life [41], encompasses several different, but related domains [42, 43] and also that functional status (i.e. Activities of Daily Living [44]), behavioural characteristics (i.e. behavioural problems

[45, 46] and depression [47]), behavioural interventions (i.e. use of restraints [48, 49], the prescription of psychotropic medication [50, 51]) and social interaction (i.e. social engagement [52, 53] as well as visits from family [54-56]) are important aspects for residents with dementia.

Figure 1. Conceptual model of the resident related study part

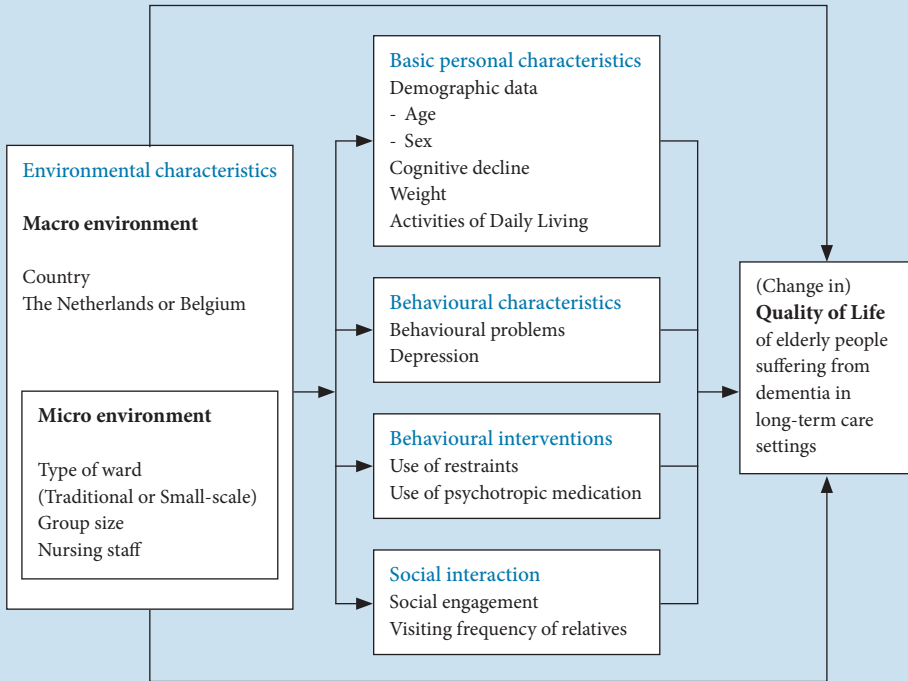
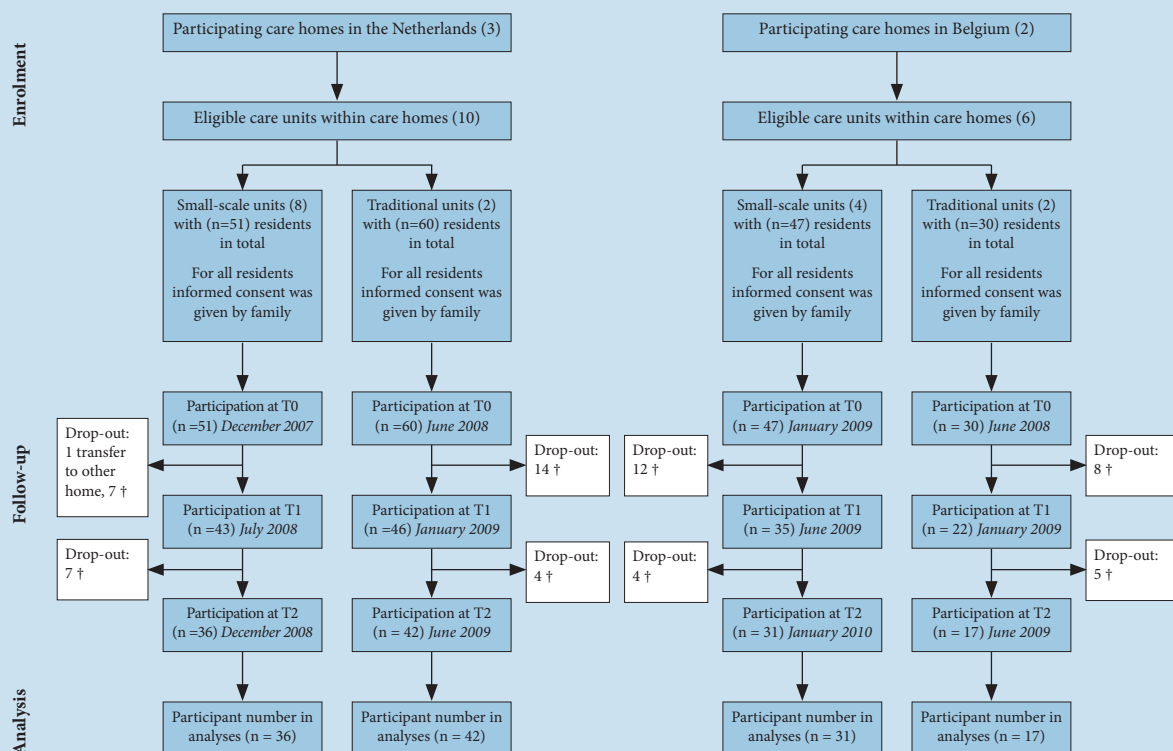


Figure 1 provides a visual representation of the underlying conceptual model, incorporating these aspects, for the resident related part of the study. The main outcome in this model is the quality of life of elderly residents with dementia in long-term care settings. The model shows two categories of influence on quality of life. The first category describes the environmental characteristics, divided into macro-environment (country) and micro-environment (type of ward, group size and nursing staff). The second category describes basic personal and behavioural characteristics, behavioural interventions and social interaction. We assume that the environmental characteristics influence quality of life both directly and indirectly through the personal, behavioural and social aspects.

Following the conceptual model, subsequently, empirical data of residents with dementia in small-scale and traditional institutional settings in both countries were collected at three measurement moments (baseline, after six months, and after twelve months). Because we knew that substantial cognitive decline of the residents with dementia would be a problem in the study, making self-report impossible, we selected research questionnaires that could be filled in by proxy-report. In this case nurses or nursing assistants who knew the resident well. At baseline 179 residents were included in the study. Drop-outs, mainly due to death, resulted

in participation of 146 residents after six months and 126 residents after a year. All observations were included in multilevel analyses. See Figure 2 for a flow diagram of participants of the resident related study part.

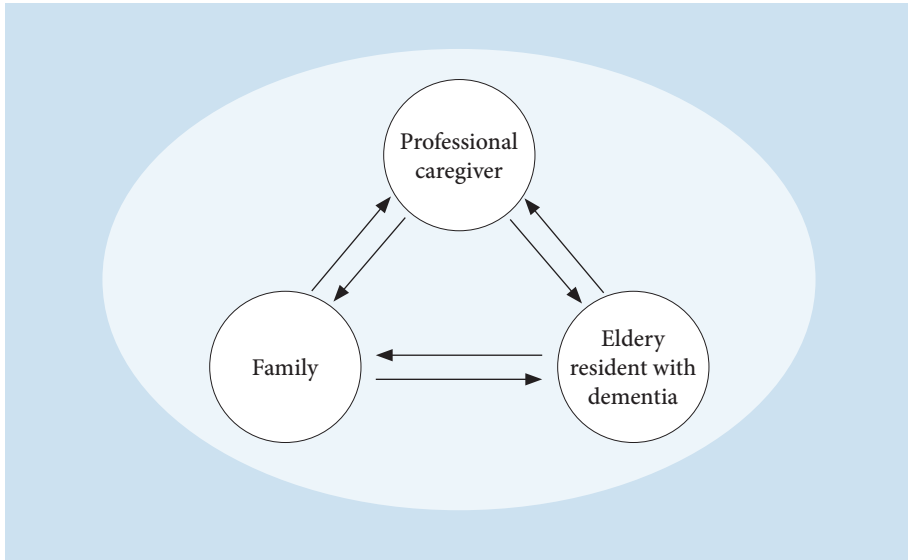
Figure 2. Flow diagram of the residents through the study



Family caregivers

To answer research question (4) regarding the *perspectives of family caregivers* a questionnaire was sent to the families of the residents that were participating in our study at baseline and after a year. The questionnaire was previously used in another study on perspectives of family caregivers [57].

When a relative with dementia is admitted to a long-term care facility, a new ‘caregiving triangle’ is established; the family caregiver, the professional caregivers of the facility and the resident with dementia inevitably have to communicate because they are partners in care. The family system is very important in this context. Research highlights a crucial need for long-term care facilities to support families, as well as the person with dementia, through the transition to a different care environment [58]. The caregiving triangle is presented in Figure 3.

Figure 3. The caregiving triangle

This caregiving triangle represents the relationships between resident with dementia, family and professional caregiver.

Professional caregivers

To answer research question (5) concerning the *professional caregivers*, a questionnaire accompanied by a letter, was sent to professional caregivers working on a permanent contract in the dementia care settings participating in our study at baseline and after a year. The questionnaire contained questions about basic personal characteristics, work-related mental health problems [59], and burnout [60].

Outline of the rest of the thesis

Chapter 2 provides an overview of the research design for the resident related part of the study and employed measurement instruments (Research Question 1).

Chapter 3 explores the benefits of small-scale living for residents with dementia, compared to traditional long-term care in the Netherlands and Belgium. The primary outcome was Quality of Life, divided into nine different domains (Research Question 2).

Chapter 4 describes how residents with dementia living in small-scale and traditional settings in the Netherlands and Belgium differ in terms of functional status, behavioural characteristics, behavioural interventions and social interaction (Research Question 3).

Chapter 5 focuses on the family caregiver perspective in traditional versus small-scale long-term care settings in the Netherlands and Belgium on the interaction between family caregiver and resident, between professional caregiver and resident, and between family caregiver and professional caregiver (Research Question 4).

Chapter 6 provides an insight into mental health problems and burnout of professional caregivers working in small-scale and traditional care settings for older people with dementia in the Netherlands and Belgium (Research Question 5).

The general discussion, Chapter 7 recaps the findings of the previous five chapters, discusses the methodologies used as well as the limitations and offers an insight into the implications of our findings for residential dementia care.

Chapters 2 to 6 were written as separate articles for international scientific journals, which can be read independently of each other.

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Quality of life of residents with dementia in long-term care settings in the Netherlands and Belgium: design of a longitudinal comparative study in traditional nursing homes and small-scale living facilities

CHAPTER 2

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Abstract

Background

The increase in the number of people with dementia will lead to greater demand for residential care. Currently, large nursing homes are trying to transform their traditional care for residents with dementia to a more home-like approach, by developing small-scale living facilities. It is often assumed that small-scale living will improve the quality of life of residents with dementia. However, little scientific evidence is currently available to test this. The following research question is addressed in this study: Which (combination of) changes in elements affects (different dimensions of) the quality of life of elderly residents with dementia in long-term care settings over the course of one year?

Methods/design

A longitudinal comparative study in traditional and small-scale long-term care settings, which follows a quasi-experimental design, will be carried out in Belgium and the Netherlands. To answer the research question, a model has been developed which incorporates relevant elements influencing quality of life in long-term care settings. Validated instruments will be used to evaluate the role of these elements, divided into environmental characteristics (country, type of ward, group size and nursing staff); basic personal characteristics (age, sex, cognitive decline, weight and activities of daily living); behavioural characteristics (behavioural problems and depression); behavioural interventions (use of restraints and use of psychotropic medication); and social interaction (social engagement and visiting frequency of relatives). The main outcome measure for residents in the model is quality of life. Data are collected at baseline, after six and twelve months, from residents living in either small-scale or traditional care settings.

Discussion

The results of this study will provide an insight into the determinants of quality of life for people with dementia living in traditional and small-scale long-term care settings in Belgium and the Netherlands. Possible relevant strengths and weaknesses of the study are discussed in this article.

Background

The substantial increase in the number of people with dementia worldwide implies that there will be much greater demand for both home care and residential care in the future [1]. For the Netherlands, the expectation is that in 2030 there will be 319,312 people with dementia, an increase of 65% over a period of 25 years [2]. The expectation for Belgium is that there will be 251,000 people aged over 65 with dementia in 2030, a rise of 56% over 25 years [3].

People usually prefer home care over residential care, but for a substantial number of people in the later stages of dementia staying at home is no longer possible [4]. In the last decade, the institutional regime in traditional, large nursing homes with a strongly medical and nursing-based approach, the hospital-like environment and the lack of privacy, has come in for heavy criticism in many countries [5-8]. To address this criticism, many large nursing home organizations are currently transforming their traditional care methods to a more homelike approach by developing small-scale living facilities [9-11]. The number of these small-scale living facilities has been increasing in many countries all over the world, such as Sweden, the United States, Germany, Belgium and the Netherlands. They take a variety of forms and the expansion is taking place at different rates in each country [5, 12, 13].

The assumption that small-scale living facilities will improve the quality of life of older persons with dementia compared to traditional nursing home care is often made by organizations that provide care for the elderly [8,14-16], as well as by politicians and other policy-makers [17-20]. However, little scientific evidence is currently available about the effects of small-scale living on the quality of life of these residents [5, 21]. Quality of life is defined by the World Health Organization (WHO) as ‘individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ [22]. The physical, psychological, social and environmental domains are considered to be the most important indicators of quality of life [22, 23].

The aim of this study is to contribute to the knowledge about the effects of small-scale living on the quality of life of residents with dementia by answering the following main research question: Which (combination of) changes in elements affects (different dimensions of) the quality of life of elderly residents with dementia in long-term care settings over the course of one year?

The relevant elements taken into account in this study are country (the Netherlands or Belgium), type of ward (traditional or small-scale), group size, nursing staff, age, sex, cognitive decline, weight, activities of daily living (ADL), behavioural problems, depression, use of restraints, use of psychotropic medication, social engagement and visiting frequency of relatives.

Methods

This study is a longitudinal comparative study of elderly residents with dementia in long-term care settings in Belgium and the Netherlands.

Sample size considerations

Sample size calculations are conducted for two groups (small-scale and traditional living) based on the primary outcome measure for residents, quality of life, as measured by the

QUALIDEM [24]. Using an effect size of 0.50, a two-sided significance level α of 0.05 and a power of 80%, about 70 participants are needed in each group. Expecting an average drop-out rate of 20%, we aim to include about 180 residents. From the five long-term care settings that were selected for this study, 179 residents can be included.

Small-scale living facilities and traditional care wards

Small-scale living facilities and traditional institutional psychogeriatric wards will be compared, based on the numerous differences between these two types of settings and the assumption that there will be a concomitant difference in the quality of life of the residents. Five long-term care settings have been selected for the study, of which two have traditional care wards and four have small-scale living wards: one of the settings has both small-scale and traditional wards. The long-term care settings were selected in advance, taking into account the comparability of the frailty of the residents. All residents willing to participate will be included in this study.

An overview of the settings can be found in Table 1.

Table 1. Wards

Country	Long-term care setting	Small-scale wards	Traditional wards	Total at T0
		N	N	N
The Netherlands	A	13	51	64
	B	24		24
	C	14		14
Belgium	D	47		47
	E		30	30
Total N		98	81	179

Belgium and the Netherlands

The choice of these two countries was primarily based on the existing collaboration between Tilburg University (the Netherlands) and K.U. Leuven (Belgium). The use of data from two different countries affords the possibility of comparison and the opportunity to learn from each other. There are also advantages as regards data collection, in that the two countries are geographically adjacent and the spoken language in both countries is Dutch. However, there are also differences, for example in legislation and the funding of long-term care, the design and number of small-scale living facilities (more facilities in the Netherlands), the group size (groups are generally smaller in the Netherlands) and the speed of development (a more rapid expansion of small-scale living can be observed in the Netherlands) [8, 25].

Study population

The study will include elderly residents over 65 years of age, with dementia and who have been admitted to a long-term care setting.

Dementia is a complex syndrome, which manifests itself in various forms and is characterized by an initially gradual and progressively deteriorating impairment of the brain functions [26]. The DSM-IV employs the presence of multiple cognitive impediments with disorders in memory functions as a criterion for diagnosing the disease [27].

The memory disorders appear in varying combinations with changes in personality, mood and behaviour [26]. Residents with dementia are often legally incapable, and the law therefore stipulates that a legal representative be appointed to look after their interests. For this study, these representatives will be asked to give informed consent on behalf of the residents [28-30].

Owing to the cognitive decline, self-reporting is often no longer possible for people with dementia. Observation by one or more professional caregivers is therefore considered to be the best, most reliable and valid alternative method of data gathering [31]. Questionnaire sets validated for the target group have been selected for the study, which can be completed by a professional caregiver, namely a nurse or nursing assistant, who is familiar with the resident. One of the questionnaires is filled in by an independent psychologist interviewing the nurse or nursing assistant who is familiar with the resident, and one will be used to gather information from the residents themselves.

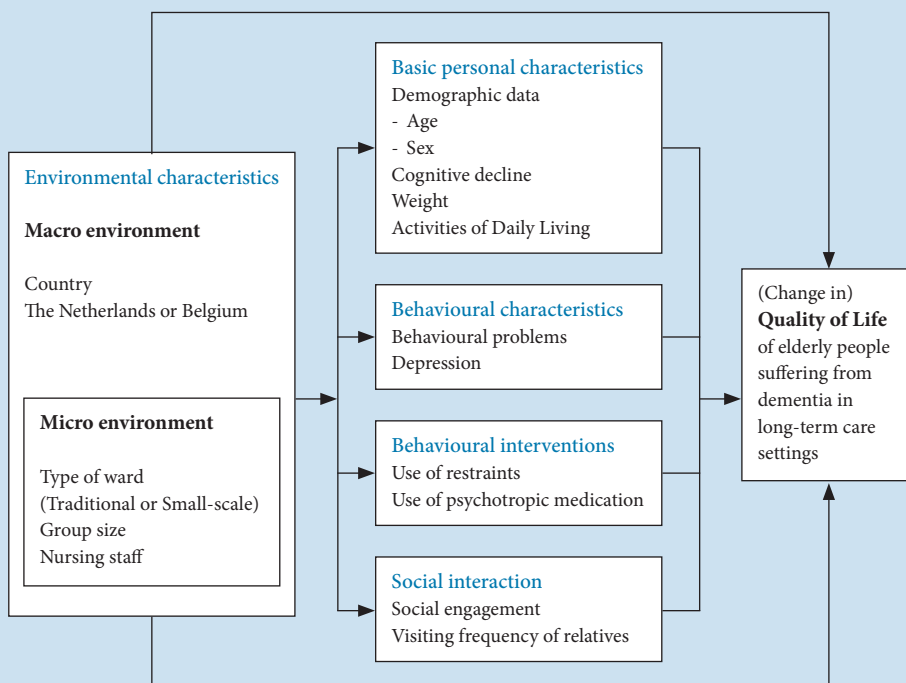
Ethical approval and informed consent

The ethics committee at De Wever, Tilburg, gave its approval for the study in September 2008. The trial is registered as ISRCTN23772945. In practice, we will consider our ethical responsibility to be to the residents and family that we wish to include in our study. There will be virtually no inconvenience to the residents, because professional caregivers will fill in the questionnaires for them. The legal representatives of the residents will receive an information brochure containing information on all aspects of the research. An informed consent form will accompany the brochure, for the representative to sign and return. Only residents for whom such consent has been given will be included in the study. All those involved will be informed that they may end their participation in the study at any time. The privacy of the participating residents will be protected and all data will be analyzed anonymously.

Conceptual model

The following conceptual model (see Figure 1) will be used to answer the research question. The model was developed after studying the most relevant factors affecting the quality of life of persons with dementia as reported in the literature [7, 32 - 51].

The main outcome in this model is the quality of life of elderly residents with dementia in long-term care settings. The model shows two categories of influence on quality of life. The first category describes the environmental characteristics, divided into macro-environment (country) and micro-environment (type of ward, group size and nursing staff). The second category describes basic personal and behavioural characteristics, behavioural interventions and social interaction. We assume that the environmental characteristics influence quality of life both directly and indirectly through the personal, behavioural and social aspects. The elements of the conceptual model will be measured using valid and reliable instruments. All scales (except for the recording of country, type of setting, age, sex and staff formation) will be measured at three moments over the course of one year: T0 (baseline), T1 (after six months) and T2 (after 12 months). An overview of the measurements and records can be found in Table 2. Most of the scales and record forms will be filled in by a nurse or nursing assistant who is familiar with the resident. One of the scales is administered by interviewing a nurse or nursing assistant, and one will be used for gathering information from the resident by an independent psychologist. All characteristics, their relation to quality of life and the proposed instruments to be used in the study are discussed below.

Figure 1. Conceptual model of the resident related study part

Quality of life

Quality of life is a broad concept. The WHO originally divided quality of life into six domains incorporating physical health, psychological state, level of independence, social relationships, personal beliefs and the relationships to features of the environment [23]. Empirical evidence from the WHO showed that a four-domain solution might fit the data better in both ill and well populations:

1. The physical domain (pain and discomfort; energy and fatigue; sleep and rest);
2. The psychological domain (positive affect; cognition, memory and concentration; self-image; appearance; negative affect);
3. Social relations domain (personal relationships; social support; sexual activity);
4. Environmental domain (safety; financial resources; availability and quality of health care; access to new information and skills; leisure time; mobility) [22, 23].

Qualidem (Quality of life in dementia) is a measurement scale used to determine aspects of the quality of life of elderly residents with dementia [24]. Using this scale, it is possible to determine how residents deal with and experience their immediate environment and what kind of relationship the elderly resident has with care giving staff and other residents. This instrument was developed and validated [52] specifically for residents in long-term care settings, over the age of 65 years and suffering from mild to severe dementia. Two professional caregivers, a nurse or nursing assistant who are familiar with the resident, observe the elderly

resident and complete the questionnaire together. In this way, the scale provides a quality of life profile of residents with dementia [53]. The questionnaire comprises 40 items that can be divided into nine subscales. The subscales need to be assessed individually and are not suitable for calculating a total score. The subscales are Caregiver relation, Positive affect, Negative affect, Restless behaviour, Positive self-image, Social relations, Social isolation, Feeling at home and Having something to do. For each item, an answer between '0 = never' and '3 = often' can be chosen. Administering the questionnaire generally takes around 15 minutes [24].

Table 2. Measurements and records

	Measurement moment		
	T0 (start)	T1 (6 months)	T2 (12 months)
Quality of life (QUALIDEM)			
Positive self-image	X	X	X
Restless behaviour	X	X	X
Feeling at home	X	X	X
Caregiver relationship	X	X	X
Social relations	X	X	X
Social isolation	X	X	X
Negative affect	X	X	X
Positive affect	X	X	X
Having something to do	X	X	X
Environmental characteristics			
Country (The Netherlands or Belgium)	X		
Type of ward (traditional or small-scale)	X		
Group size	X		
Nursing staff	X		
Basic personal characteristics			
Demographic data			
- Age	X		
- Sex	X		
Cognitive decline (S-MMSE)	X	X	X
Weight (Dossier)	X	X	X
Activities of daily living (Barthel Index)	X	X	X
Behavioural characteristics			
Behavioural problems (NPI-NH)	X	X	X
Depression (CSDD)	X	X	X
Behavioural interventions			
Use of restraints (Dossier)	X	X	X
Use of psychotropic medication (Dossier)	X	X	X
Social interaction			
Social engagement (RISE from RAI)	X	X	X
Visiting frequency of relatives (Questionnaire relatives)	X	X	X

Environmental characteristics

The relevance of country and type of ward for quality of life has already been discussed. Group size is an important factor from the micro-environment, because wards can vary in the number of residents (between six and 27), and nursing staff is an important factor, because staffing levels and education level can differ. At T0 country (the Netherlands or Belgium), type of ward (small-scale or traditional), group size (between six and 27) and nursing staff (staffing levels of qualified nurses and of other assistant staff) are recorded.

Basic personal characteristics

Demographic data

As regards the basic personal data of the residents, their age and sex will be recorded at T0.

Cognitive decline

To provide an indication of the level of cognitive impairment, cognitive decline is included in the conceptual model. Cognitive decline has been shown to correlate with factors that are important for the quality of life, such as the occurrence and severity of problematic behaviours [33] and activities of daily living [34].

The Standardized Mini Mental State Examination (SMMSE) measures the cognitive decline of the elderly person as the dementia progresses. In order to diagnose the severity of the influence of the disease on cognition and motor skills, the elderly person with dementia is asked to answer a series of 11 questions. For example, the resident is asked where he or she is, why they are there, what day of the month it is, to remember some words, write a sentence, copy a drawing and perform a few tasks (closing eyes/folding paper). The maximum possible test score is 30 [54]. The scale has been validated using psychometric analyses, with the conclusion that the S-MMSE is a reliable instrument and a valuable tool for assessing cognitive function [55]. The scale has a cut-off value of 27 for highly educated persons and 24 for lower-educated individuals [56].

Weight

Body weight can be considered as a general measure of health status. It is known that many persons with dementia begin to lose weight shortly after the onset of the disease due to a variety of physiological, psychological, medical and environmental factors [57, 58]. Moreover, the literature shows that changes in the environment may improve nutritional intake [57]. This factor is therefore considered to be of relevance for this study and the most recent weight of the resident in kilograms, fully clothed and with shoes on, is taken from the personal records of the resident.

Activities of Daily Living (ADL)

Activities of daily living (ADL) may be considered as an indication of functional status. The literature shows that fostering ADL independence has a positive effect on the quality of life of persons with dementia [35, 36].

ADL can be measured using the Barthel Index, which includes ten basic activities of daily living, namely personal hygiene, using the toilet, getting dressed, walking up and down stairs, bathing, mobility, (in)continence, requiring assistance in transferring from bed to chair, and requiring assistance with feeding. The scale is completed by a nurse or nursing assistant working in the facility who is familiar with the resident, and takes about five minutes. A score of 0 to 2 or 0 to 3 is recorded for each activity. The maximum possible score is 20. A score of

0 to 4 = Completely dependent on others; 5 to 9 = Requires lots of help; 10 to 14 = Needs help but can do things alone, 15 to 19 = Reasonably independent, and 20 = Completely ADL-independent [59]. The Barthel Index is a valid and reliable measure [60].

Behavioural characteristics

Behavioural problems

Behavioural problems, such as delusions, hallucinations, agitation, depression, anxiety, elation, apathy, disinhibition, irritability, aberrant motor behaviour, sleep problems and eating disorders are frequently seen in elderly people with dementia. Studies report that on average, mild to severe behavioural problems occur in 64% of cases of dementia [39], and that between 80% [40] and 90% [41] of all elderly people with dementia will develop at least one symptom of behavioural problems during the entire course of their disease. These problems cause distress and influence the quality of life not just of the elderly person concerned, but also of their family and professional caregivers [42].

The Neuropsychiatric Inventory - Nursing Home version (NPI-NH) questionnaire can be used by an independent psychologist to interview a nurse or nursing assistant working in the facility, who is familiar with the resident, about possible neuropsychiatric symptoms from which an elderly person is suffering. These symptoms include delusions, hallucinations, agitation/aggression, phobia, uninhibited behaviour, depression/ dysphoria, euphoria, apathy/ indifference, neuroticism, aimless repetitive behaviour, eating disorders and sleeping disorders. The NPI-NH gives an insight into the severity (1 to 3), frequency (1 to 4) and workload (0 to 5) of each of the separate behavioural disorders [61]. A total NPI-NH score can be calculated by adding together all twelve component scores (which are the product of the frequency and severity scores) [62]. Administering the questionnaire generally takes about 15 minutes. The psychometric properties and factor structure of the NPI-NH have been assessed, showing internal consistency, reliability, convergent validity and discriminant validity [63].

Depression

People with dementia often suffer from depressive symptoms, such as sadness, lack of energy, low reactivity to pleasant events and multiple physical complaints [43, 44]. These depressive symptoms have been shown to correlate negatively with quality of life [45].

The Cornell Scale for Depression in Dementia (CSDD) was developed specifically for identifying depressive symptoms in elderly people with dementia [43]. The CSDD incorporates mood, behavioural disorders, physical characteristics of depression and cyclical functions and disorders in cognitive content. A nurse observes the elderly person and fills in an observational scale (containing 19 items and ranging from: a = cannot be judged, 0 = absent, 1 = mild, 2 = severe). The item scores are added together. Scores above 10 indicate a probable major depression. Scores above 18 indicate a definite major depression. Scores below six are generally associated with absence of significant depressive symptoms [43]. The CSDD has been assessed as a valid screening tool for depression in the elderly, being equally valid in populations with and without dementia [64].

Behavioural interventions

Use of restraints

The use of restraints, including physical restraints (belts), is common practice in the long-term

care setting [46, 47]. Since these measures are not always effective and have other known negative physical, psychological and social consequences, their usage will influence quality of life [46, 47]. Therefore, the number and type of restraints used by the resident are recorded. The range of restrictive measures includes fixation with belts, such as a large bed belt, a small bed belt, a fastening belt in a chair or wheelchair, securing the person to the bed with a blanket, using an adjustable tabletop in chair, restraining of limbs and the use of bedrails, but also the application of technological restraints such as movement detection mats or movement detection sensors in the bedroom.

Use of psychotropic medication

The use of psychotropic medication is common among residents with dementia in long-term care settings. It is known that the use of this type of medication may have a detrimental effect on quality of life [48-50]. The use and number of sedatives, antidepressants and antipsychotics is taken from the actual medication file in the personal notes of the resident.

Social interaction

Social engagement

Participation in joint activities, such as drinking coffee together, active or passive participation in a game or taking a walk together, is related to a higher quality of life [51], while activities such as interacting with a pet and making music as part of a group have been shown to provide positive cognitive stimulation in persons with dementia [6].

The Revised Index for Social Engagement (RISE) measures the social involvement of elderly residents suffering from dementia with other residents, professional caregivers and relatives. The scale contains eight questions about the social interaction of the resident. A nurse or nursing assistant who is familiar with the resident completes the questions by marking whether or not the specific social situation mentioned in the question has occurred over the last seven days. Completing the questionnaire takes about five minutes. RISE is one of the scales derived from the larger instrument Resident Assessment Instrument 2.0 (RAI 2.0) [65]. The RAI 2.0 is used to assess a variety of factors related to the functioning of elderly residents in care homes [66]. The reliability and validity of the RISE has been assessed individually and it was found to be a valuable and stable measure for assessing social engagement in nursing homes [67], including patients with cognitive impairments [65]. The scale does not have an established cutoff value.

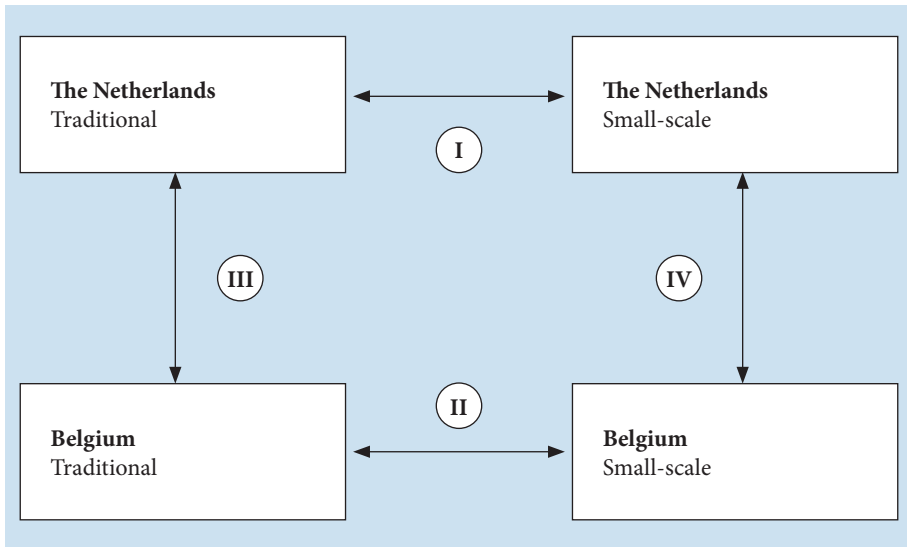
Visiting frequency of relatives

The relationship with relatives is important for residents with dementia, because this relationship may have a positive influence on the behavioural and psychological symptoms of the disease [68, 69]. A nurse or nursing assistant who is familiar with the resident will record whether the resident has visitors: almost every day, once or twice a week, once every two weeks, once a month or less than once a month.

Analyses

Comparisons will be made in the analysis to explore whether there are differences in the combination of elements that influence the quality of life of residents living in a long-term traditional or small-scale setting in the Netherlands and in Belgium.

To enable comparison of quality of life in the two countries and in both types of wards, the comparative analyses shown in Figure 2 will be central.

Figure 2. Comparisons

The two types of settings will be compared within each country. Additionally, the Dutch small-scale living facilities will be compared with their Belgian counterparts. The same comparison will be made for the traditional wards in both countries.

To make a comparison, the data will be analyzed using descriptive, quantitative and qualitative analyses. The quantitative analyses will include cross-sectional and longitudinal analyses using SAS 9.2.1©. The null hypothesis that ‘the patterns of change in the mean response over time on the Qualidem subscales are the same in both types of long-term care settings’ will be tested. The qualitative analyses will be carried out using Qualitative Comparative Analysis using TOSMANA© [70]. One of the general advantages of QCA is that it combines the strength of qualitative research (within-case knowledge) with the strength of quantitative enquiry (cross-case comparison) [71]. The most conventional and intuitive type of QCA analysis will be employed for the analyses: crisp-set Qualitative Comparative Analysis (csQCA). In csQCA, a dichotomous data table will be built, based on within-case knowledge, and from this dichotomous data table a set of necessary and sufficient conditions leading to a certain outcome will be deduced [72].

This approach integrates key strengths of both qualitative (case-oriented) and quantitative (variable-oriented) methods and allows triangulation. It provides a double check to ensure that valid results are obtained despite the relatively small number of participants.

Discussion

This study will provide an insight into determinants of quality of life for people with dementia living in traditional and small-scale long-term care settings in Belgium and the Netherlands. Due to ethical considerations, a randomized controlled trial is impossible. Although they have

been selected based on their similar view of care giving, the small-scale and traditional wards in the two countries are not entirely comparable. This could potentially influence the results of the study. There are differences in legislation as well as in the organization and implementation of residential care between both countries.

Moreover, the settings are real-life care settings and have specific characteristics that may vary within and between countries. The analyses will therefore be controlled for relevant differences between and within countries, such as group size, differences in the length of existence of the small-scale living facilities (ranging from September 2006 to December 2007) and differences in nursing staff, and for significant variations in the basic data of the residents.

Due to the age and frailty of the participants and the fact that the study will be conducted over the course of an entire year, there will be drop-outs, mainly due to death or occasionally to residents being moved to another institution.

Despite these limitations, collecting data from residents on various different elements, in different countries and different types of ward provides added value, because of the learning aspects and because it may enable certain patterns in the data to be discerned more clearly.

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Quality of life of residents with dementia in traditional versus small-scale long-term care settings: A quasi-experimental study

CHAPTER 3

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Abstract

Background

The number of people living with dementia worldwide is increasing, resulting in a need for more residential care. In response to criticism of the traditional medical approach to residential dementia care, many large nursing homes are transforming their traditional care facilities into more home-like small-scale living facilities.

Objectives

This study examined the assumed benefits of small-scale living for residents with dementia, compared to traditional long-term care in the Netherlands and Belgium. The primary outcome was quality of life, divided into nine different domains.

Design

The study had a longitudinal design within a one-year time interval.

Settings

Five long-term care settings in the Netherlands and Belgium containing four traditional and twelve small-scale living units participated in the study.

Participants

Data were obtained from 179 residents with dementia (age > 65 years) (Dutch small-scale N = 51, traditional N = 51, Belgian small-scale N = 47, traditional N = 30).

Methods

Nurses and nursing assistants were trained to fill in the questionnaires.

Results

In the Dutch sample, residents in small-scale settings had higher mean scores on 'social relations', 'positive affect', and 'having something to do' than residents in traditional settings. Moreover, mean scores on 'caregiver relation' and 'negative affect' remained stable over time among residents in small-scale settings, but decreased in traditional settings. These differences could not be explained by differences in behavioural characteristics, behavioural interventions, or social interaction. In the Belgian sample, fewer differences were found between traditional and small-scale settings. Nevertheless, residents in small-scale settings were reported to experience less 'negative affect' than those in traditional settings, which could be explained by differences in depression. Over time, however, residents 'felt more at home' in traditional settings, whereas no such increase was found for small-scale settings. Moreover, the mean quality of life scores on 'restless behaviour', 'having something to do' and 'social relations' decreased in small-scale settings, but remained stable in traditional settings.

Conclusions

Both small-scale and traditional settings appear to have beneficial effects on different domains of quality of life of residents with dementia. Future research should focus more on the quality and content of the care provided, than on the effects of the scale and design of the environment in long-term care settings.

Introduction

Every year, 4.6 million people throughout the world are diagnosed with dementia [1]. It is estimated that approximately 63 million people worldwide will suffer from dementia by 2030 [2]. The progression of dementia depends on the nature, distribution and severity of brain abnormalities in the individual. It manifests itself in various forms and is characterized by an initially gradual and progressively deteriorating impairment of the brain functions [3]. It is a disease that is always associated with a need for care [4]. Memory disorders occur in varying combinations with changes in personality, mood and behaviour [3]. This is also seen in everyday practice of a nursing home in which this study originated. People usually prefer home-based care over residential care, but for a substantial number of people in the later stages of dementia, staying at home is no longer possible [5], resulting in a growing demand for residential care.

Traditionally, residential dementia care has taken a medical and nursing-based approach. Over the last decade, however, this approach has been criticized for focusing mainly on the care aspects, and it has been argued that the emphasis in dementia care should move towards creating an environment which offers a better balance between living, well-being and care [6]. In response to this criticism, many large nursing homes are currently transforming their traditional care environments to fit in with a more home-like, holistic and person-centred approach [7, 8]. Small-scale living for older persons with dementia is a relatively new form of long-term care designed to bring about this envisaged transformation [9-11].

Although there is currently no widely accepted conceptual definition or commonly used way of organizing small-scale living facilities, they share essential characteristics in their vision on care and care practice. For example, residents live in a home-like environment with relatively small groups. Moreover, the focus is on enabling residents to continue their habitual activities of daily life. They are encouraged to maintain their original lifestyle and to keep up the activities and hobbies in which they engaged at home for as long as possible. In addition, the number of professional caregivers in small-scale living facilities is relatively small, and their tasks are more integrated and less specialized than in traditional wards [12, 13]. Hence, residents and family caregivers come into contact with fewer professional caregivers, who moreover get to know the resident and family member(s) better. Consequently, there is more emphasis in small-scale facilities on social relations between the family, the resident and the professional caregiver than is the case in traditional settings.

Organizations that provide residential care for older people, as well as politicians and policymakers, often assume that the quality of life (QoL) of older persons with dementia is better in small-scale living facilities than in traditional nursing home care [14, 15]. For many years now, quality of life has been an important concept within health services and is also an issue in research on small-scale living facilities for residents with dementia [16]. To date, however, only a few studies have compared the QoL of residents with dementia in small-scale and traditional settings. Moreover, those studies that have been conducted [13, 17], mainly examined overall differences in QoL. Nevertheless, when it is no longer possible to live at home and persons with dementia have to move to an institution, a broader multidimensional concept of quality of life may be preferable to assessing the concept in its totality [18]. Therefore, the goal of the present study was to examine whether people with dementia living in traditional and small-scale long-term care settings achieve different scores on QoL domains. An additional goal was to examine how any differences found between residents in these settings can be

explained. For this purpose, data were collected among residents of small-scale and traditional settings in the Netherlands and Belgium.

To set up the framework for the study, we conducted a literature review to determine symptoms of dementia that could possibly differ between settings [19]. The most relevant factors affecting the QoL of persons with dementia in traditional and small-scale long-term care settings were found to be:

- behavioural characteristics:
 - behavioural problems [20, 21]
 - depression [22]
- behavioural interventions:
 - use of restraints [23, 24]
 - prescription of psychotropic medication [25, 26]
- social interaction:
 - social engagement [27, 28]
 - visits from family [29-31]

Ettema et al. [32] examined what quality of life is for people with dementia, based on a literature study, on the theoretical background of the adaptation-coping model [33]. Accordingly, quality of life for older people with dementia can be divided into nine different domains: caregiver relation, social relations, social isolation, having something to do, positive affect, positive self-image, negative affect, feeling at home, and restless behaviour [32].

Due to the specific characteristics of small-scale living compared to traditional settings, we expected that residents living in these facilities would differ on some, but not on all of these QoL domains. For example, previous research does not indicate differences between small-scale and traditional living units on domains relating to positive affect, positive self-image, and feeling at home. Therefore, comparable results for both types of settings may be expected on these domains [13, 17].

At the same time however, there is reason to believe that residents in small-scale living units will, compared to residents in traditional wards, score better on the relational domains of QoL (i.e. caregiver relation, social relations, social isolation, and having something to do). More specifically, the different vision of care and the organizational structure in small-scale living settings- with their home-like character and smaller groups - are likely to lead to more intensive contact between residents, family and professional caregivers in small-scale settings than in traditional settings. This, in turn, can lead to relatively more social engagement in small-scale facilities than in traditional dementia care units. Results from previous studies confirm that residents with dementia can benefit from social interaction [31]. Moreover, studies on small-scale living have found that residents in small-scale care facilities, compared to residents living in traditional units, are more frequently engaged in verbal communication [34], show more interest in their surroundings [35], have better relationships with others in the nursing home [9], and generally seem to be more socially engaged [17]. Since the focus in small-scale facilities is on enabling residents to continue living as they were used to doing in their own home, it is also conceivable that residents in such facilities will also score better on having something to do.

It is also possible that, compared to traditional settings, residents in small-scale units perform better on the QoL domain negative affect, although the evidence for this is somewhat mixed [22, 36]. For example, previous studies have found that 80% of all nursing home residents with dementia develop at least one symptom of behavioural problems during the entire trajectory of the disease [37], and one third also have depressive symptoms [38]. Two studies in small-scale living facilities found that residents reported fewer depressive symptoms [34], and had better emotional health compared to residents in traditional nursing home care settings [9]. Yet, a recent study in the Netherlands found no differences in the average

depression scores of residents in small-scale living and traditional long-term care settings [13]. In terms of behavioural problems, previous studies have shown that, after relocating residents to small-scale living facilities, behavioural problems temporarily increased, but that this effect had disappeared after a year [39]. More recent studies have also found no effects of small-scale living on behavioural problems [13, 17].

With regard to restless behaviour it is possible that residents in small-scale settings display more restless behaviour compared to residents in traditional wards, because both psychotropic medication and restraints tend to be employed less frequently in these settings [17], due to the home-like vision of care [13]. Use of restrictive devices and prescription of psychotropic medication are also minimized in small-scale settings is also done because research shows that both are often ineffective or can even be dangerous [24, 26]. However, rationales for prescribing psychotropic medication and using restraints are also concerned with highly personal and disease-related factors. Pro's and con's therefore have to be considered in each case, because by not using them the freedom of movement is increased, but may also have opposing effects, leading to a possible increase in restless behaviour in small-scale facilities.

Setting the scene

The present study was conducted in two countries (the Netherlands and Belgium), which provided the possibility to examine whether the small-scale vision of care yields a similar pattern of results in different countries. The Netherlands and Belgium were chosen because they have comparable small-scale living facilities, and because they share the same native language (Dutch), which allowed us to use the same measurement instruments. Moreover, both countries are welfare states, providing services for everyone in need of long-term care. Although the vision and implementation of small-scale living is similar in both countries, there are also some differences. Belgium has a relatively longer history than the Netherlands of providing small-scale long-term care for people with dementia [15]. The number of residents living together in a small-scale setting also tends to be larger in Belgium than in the Netherlands¹. Furthermore, there has been a substantial increase in the number of small-scale living settings in the Netherlands over the last decade [40], whereas this is not the case in Belgium. There are also some differences between countries in the financing and funding of residential care for older people [14, 41]. In the Netherlands, long-term care settings are mostly organized in large, non-profit foundations, while in Belgium the settings are stand-alone, private non-profit entities. Funding in the Netherlands is based on a system of Care Severity Packages provided by the government to fund facilities that can in turn be used to provide care for individual residents [42]. Residents are obliged to make an income-dependent contribution [43]. In Belgium, nursing homes are funded partly by the federal government and partly by the regional authorities. Additionally, residents have to pay a daily fee for food and lodging.

Method

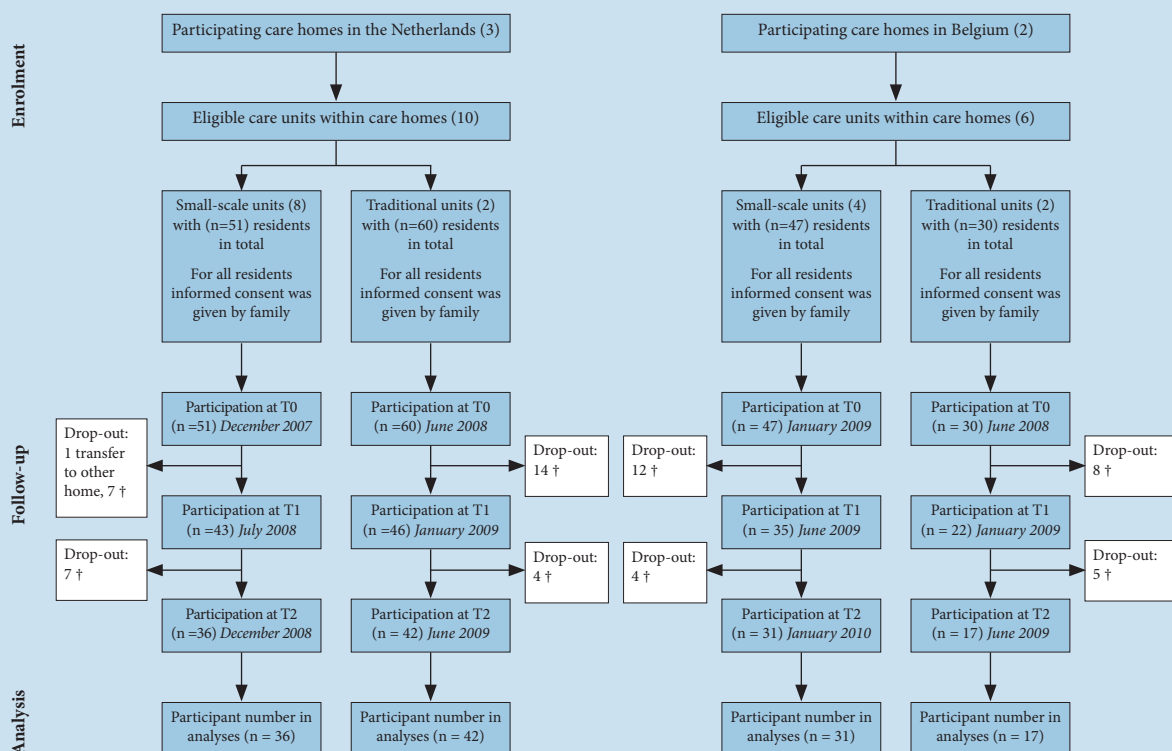
The study had a quasi-experimental design, with three measurement moments within a period of one year. Data were gathered at baseline, after six months and after twelve months in traditional and small-scale long-term care settings in the Netherlands and Belgium. Comparisons between the two types of setting were made within each country.

¹ This generally means between six and eight residents in the Netherlands, and between six and nine in Belgium, although groups in Belgium are sometimes extended to between 12 and 15 residents due to funding issues.

Sample

This study examines the assumed benefits of traditional and small-scale living facilities on the quality of life of residents with dementia within the Netherlands and Belgium. Residents in traditional living facilities were used as the control group. Five long-term care settings, incorporating four traditional and twelve small-scale units in the south of the Netherlands and in the north of Belgium were approached for the study and were willing to participate. The settings were in the vicinity of the universities involved and had pre-existing collaboration arrangements within the academic network. Data were obtained from all 179 residents with dementia aged over 65 years, who had been assessed as being in need of psychogeriatric care. Informed consent was given by the legal representatives of the residents. See Figure 1 for a flow diagram containing participant numbers in each setting at the different measurement moments. Sample size calculations were performed for two groups (small-scale and traditional living facilities) based on the primary outcome measure for residents, quality of life, as measured by QUALIDEM. Using an effect size of .50, a two-sided significance level α of .05 and a power of 80%, 70 participants were needed in each group. Based on an expected average drop-out rate of 20%, we aimed to include about 180 residents. From the five long-term care settings that were selected for this study, 179 residents could be included.

Figure 1. Flow diagram of participants through the study



Procedure

After studying the factors affecting the quality of life of persons with dementia, a literature review was performed to find suitable, valid and reliable questionnaires for the primary outcome quality of life. Questionnaires were selected which were applicable for older people in all stages of dementia. These questionnaires were available in the residents' native language (Dutch) and they were relatively short, making administration of all questionnaires together feasible. Methods that allow residents to rate their own QoL are preferred, if their judgment permits this. Due to their cognitive impairment, none of the residents in this study were, however, able to self-report. Observation by one or more professional caregivers was therefore considered to be the best, most reliable and valid alternative method of data gathering [44]. Questionnaires assessing depression, social engagement, visiting frequency of relatives, functional status and quality of life were completed by one or two nurses or nursing assistants who knew the resident well. They were trained to fill in the questionnaires and worked in a single unit, blind to other participating units. Behavioural problems were assessed by an independent psychologist interviewing the nurse or nursing assistant, while cognitive impairment was assessed by an independent psychologist interviewing the residents themselves. All questionnaires were completed at three measurement times (at baseline, after six months and after 12 months) to avoid the risk that the findings would represent only a random indication at a specific moment in time. Demographic data (age, sex, country and setting) were obtained from the personal files of the residents at baseline. This study was part of a project registered under trial number: Current Controlled Trials ISRCTN23772945. The study protocol was published elsewhere [19]. This study does not deviate from the original study protocol, but it focuses on part of the design of the overall study, making within-country comparisons between types of settings on the primary outcome Quality of Life.

Measurement instruments

To answer the research question, three types of valid and reliable measurement instruments were employed: instruments to measure the primary outcome quality of life, secondary outcomes being quality of life determinants, and control variables.

Primary outcome Quality of Life

Quality of life The QUALIDEM (Quality of life in dementia) was used, which is a tool developed for measuring quality of life for people with dementia [32]. This instrument was chosen because it has been developed and validated specifically for residents in long-term care settings, over the age of 65 years, with mild to severe dementia, and assesses nine domains of QoL. QUALIDEM comprises 37 items on a four-point scale (range 0-3) assessing the domains caregiver relation (7 items), positive affect (6 items), negative affect (3 items), restless behaviour (3 items), positive self-image (3 items), social relations (6 items), social isolation (3 items), feeling at home (4 items) and having something to do (2 items). A higher score on a subscale indicates a higher QoL.

Secondary outcomes

Behavioural characteristics. Behavioural problems were assessed using the NPI-NH (Neuropsychiatric Inventory - Nursing Home Version) [45]. Depression was measured using the CSDD (Cornell Scale for Depression in Dementia), which was specifically developed to identify depressive symptoms in older people with dementia [46].

Behavioural interventions. The use of physical restraints, being any limitations imposed

on an individual's freedom of movement [24], including their number and type, was recorded as absent or present from the personal files of the residents. The range of restraining measures was limited to and included fixation with belts, including small and large bed belts, (wheel) chair belts, securing the person to the mattress with a sheet, using a fixed table top in a chair, use of bilateral full-enclosure bedrails, and use of sensor mats and infrared sensors (motion alarms) in the bedroom.

The number of different and actually taken psychotropic medications was taken from the medical files of the residents. Psychotropic medication was divided into three types: sedatives, antidepressants and antipsychotics [47].

Social interaction. Social engagement was measured using the RISE (Revised Index of Social Engagement), which is a subscale taken from the larger Resident Assessment Instrument 2.0 (RAI 2.0) [27]. The visiting frequency of relatives was recorded by a nurse or nursing assistant on a five-point scale ranging from 'almost every day' to 'less than once a month'.

Control variables

Basic personal characteristics. Cognitive impairment was measured using the S-MMSE (Standardized Mini Mental State Examination) [48], and was included to control for the possible influence of cognitive differences on QoL. Activities of daily living (ADL) were measured using the Barthel Index [49], and were included to control for the possible influence of functional differences on QoL.

Analytical strategy

The data formed a hierarchically nested or multilevel data structure: observations over time were nested within persons, which were then nested within settings. Accordingly, the data were analyzed using Hierarchical Linear Modeling techniques [50]. The primary analyses were three-level models, and each quality of life subscale was analyzed separately.

A first set of analyses estimated means for the different quality of life subscales and compared these means across the traditional and small-scale settings in the Netherlands and Belgium. This was done by estimating "unconditional models" at level 1 and 2, and estimating "no intercept models" at level 3. In these no-intercept models, the traditional and small-scale settings in Belgium and the Netherlands were represented by dummy-coded variables, and these analyses produced separate coefficients (representing mean scores) for each type of facility in each country. In a series of follow-up analyses, these coefficients were compared using "tests of fixed effects" [51, 52]. In these analyses, the means of the traditional and small-scale settings were compared in Belgium and the Netherlands. In an additional series of analyses, relevant background variables (e.g. sex, age, cognitive impairment, functional status) were included at level 2 (using a forward stepping procedure) to examine whether they influenced the results. A series of follow-up analyses then examined whether differences between traditional and small-scale settings could be explained by depression, behavioural problems, use of restraints, and actual use of psychotropic medication, social engagement and visits.

A second set of analyses examined changes over time on the different quality of life subscales for traditional and small-scale settings in the Netherlands and Belgium. To this end, time of measurement (at baseline, after six months and after a year, coded as 0, 1 and 2, respectively) was added at level 1. At level 2, no predictors were entered, and at level 3 differences in the Time slope between traditional and small-scale settings within the Netherlands and Belgium were examined by bringing up the Time slope from level 1 and by estimating mean slopes for each type of living facility in each country².

² Following recommendations by multilevel modelers [53] effects were initially modeled as random, but were modeled as fixed when the random variance associated with an effect was not significant.

Results

Basic personal characteristics

An overview of basic personal characteristics of residents in the small-scale and traditional settings in the Netherlands and Belgium, including age, gender, cognitive and functional status, is presented in Table 1. Participants in the four groups were mainly women with an average age ranging from 84 to 89 years old. An absolute difference could be seen in cognitive impairment between the groups, which was however not statistically significant. Nevertheless, the Dutch traditional and small-scale groups differed significantly in their ADL scores (Table 1).

Table 1. Characteristics of residents (N=179) in traditional and small-scale settings in the Netherlands and Belgium

	Netherlands Traditional (A) (2 wards, n=51)	Netherlands Small-scale (B) (8 wards, n=51)	Belgium Traditional (C) (2 wards, n=30)	Belgium Small-scale (D) (4 wards, n=47)
Age in years, M(SD)	83.99 (5.12) ^C	84.50 (5.86) ^C	89.09 (5.67) ^{A, B, D}	84.52 (7.05) ^C
Women (%)	34 (67%)	41 (80%)	25 (83%)	42 (89%)
S-MMSE (0-30) ¹	4.96 (5.59)	7.61 (6.26)	8.10 (8.06)	6.07 (5.57)
Barthel Index (0-20) ¹	5.25 (4.91) ^{B, D}	8.58 (5.61) ^A	5.93 (5.61)	8.55 (4.69) ^A

Note: F-tests were conducted and letters are assigned to groups (A, B, C, D) in superscripts indicating significantly different pairs (following Bonferroni correction) at the $p < .01$ level, two-tailed.

¹ Higher scores mean better cognitive skills (S-MMSE) and better ADL (Barthel Index).

Mean differences in quality of life between traditional and small-scale settings

Table 2 presents an overview of the (unadjusted) mean scores aggregated over the three measurement moments on the different QoL subscales in traditional and small-scale settings in the Netherlands and Belgium. The results show that residents in small-scale settings in the Netherlands were reported to have better social relationships than residents in traditional settings. Moreover, the mean score on 'positive affect' was significantly higher for residents in small-scale Dutch settings than in traditional Dutch settings. The analyses also indicated higher mean scores on 'having something to do' in small-scale settings. This means that, compared to traditional settings, residents in small-scale settings were more inclined to help with group tasks and performed more personal activities. For the remaining QoL subscales, no significant differences were found between Dutch traditional and small-scale settings.

In the Belgian samples, fewer significant differences were found in the mean quality of life scores between traditional and small-scale settings. The analysis only revealed a significant difference for quality of life on the aspect 'negative affect', such that the mean QoL was higher among residents in small-scale Belgian settings than in traditional Belgian settings. Additional analyses in which we controlled for relevant background variables (sex, age, cognitive impairment, functional status) yielded a similar pattern of results in both countries.

Table 2. Within-country comparisons of means (aggregated across time) for quality of life subscales by type of setting

Subscale (Range)	The Netherlands		Belgium	
	Traditional (n=51)	Small-scale (n=51)	Traditional (n=30)	Small-scale (n=47)
Caregiver Relation (0-21)	14.36	14.66	14.21	14.80
Positive Affect (0-18)	10.85 ^{a***}	14.12	11.87	12.56
Negative Affect (0-9)	5.97	5.54	4.59 ^{b**}	6.00
Positive Self-Image (0-9)	7.42	7.61	6.24	6.74
Social Relations (0-18)	8.30 ^{c***}	10.97	10.37	10.40
Social Isolation (0-9)	6.34	6.14	5.48	5.82
Having Something to Do (0-6)	0.91 ^{d***}	2.43	1.58	2.11
Feeling at Home (0-12)	10.23	9.56	8.94	9.37
Restless Behavior (0-9)	4.63	5.11	4.30	3.81

Note: The level 1 model in these analyses was as follows: $y_{ij} = \pi_{0ij} + e_{ij}$. In this model, y_{ij} is a quality of life measure at time t for person i in ward j , π_{0ij} is a random coefficient representing the mean of y for person i in setting j , and e_{ij} represents the error associated with each measure. The level 2 model was: $\pi_{0ij} = \beta_{00j} + r_{0ij}$. In this model, β_{00j} is the mean on a quality of life measure in setting j , and r_{0ij} is a random “setting” effect (i.e. the deviation of person ij ’s mean from the setting mean in a small-scale setting in the same country). Higher scores indicate better QoL.

^a $p = .000$, ^b $p = .002$, ^c $p = .000$, ^d $p = .000$, ^{**} $p < .01$, ^{***} $p < .001$.

Behavioural characteristics, behavioural interventions and social interaction

To examine the possibility that differences in the effects of traditional and small-scale settings on quality of life domains might be due to differences in behavioural characteristics, behavioural interventions or social interaction, a series of follow-up analyses was performed. A first set of analyses estimated means for behavioural characteristics, behavioural interventions and social interaction, and compared these means between traditional and small-scale facilities in the Netherlands and in Belgium (see Table 3).

For the Dutch sample, these analyses revealed that the mean score on social engagement (RISE) was higher for the small-scale facilities than for traditional wards. In an additional set of analyses, positive relationships were found between social engagement on the one hand and the quality of ‘social relations’ ($\beta = 1.03$, $p < .001$), ‘positive affect’ ($\beta = 0.88$, $p < .001$) and ‘having something to do’ ($\beta = 0.32$, $p < .001$) on the other. The mean differences between Dutch traditional and small-scale facilities on these three measures remained, however, after adding social engagement at level 1 to the model. Thus, the results indicate that differences in social engagement cannot explain the higher scores on these quality of life subscales in Dutch small-scale facilities.

For the Belgian sample, the analyses revealed that the mean score on depressive symptoms (CSDD) was higher for traditional wards than for small-scale units (see Table 3). An additional analysis also revealed that depressive symptoms (CSDD) were related to more ‘negative affect’ ($\beta = -0.13$, $p < .001$). Mean differences in ‘negative affect’ between Belgian traditional and small-scale facilities disappeared after adding depressive symptoms to the model at level 1 ($p = .06$). Thus, depressive symptoms seem to explain differences in the ‘negative affect’ QoL subscale in the Belgian traditional and small-scale wards.

Table 3. Within-country comparisons of means (aggregated across time) for behavioral characteristics, behavioral interventions and social interaction by type of setting

Measure (Range)	Netherlands		Belgium	
	Traditional (n=51)	Small-scale (n=51)	Traditional (n=30)	Small-scale (n=47)
Social Engagement (0-8)	2.43 ^{a**}	3.69	2.52	2.71
Visits (1-5)	2.27	1.95	2.25	2.07
Use of Restraints (#)	1.11	1.18	1.11	1.16
Prescription of Psychotropic Medication (#)	1.47	1.29	1.68	1.99
Depression (0-38)	8.45	8.37	10.27 ^{b†}	8.50
Behavioural Problems (0-144)	17.53	21.43	15.75	17.57

Note: A higher score indicates more social engagement (rate 0-8 activities in the past two weeks), fewer visits (1 = almost every day, 2 = once or twice a week, 3 = once every two weeks, 4 = once a month or 5 = less than once a month), a higher number of absolute restraints and prescribed medications, higher depression and more behavioural problems.

^{**} $p < .01$, [†] $p < .10$, ^a $p = .004$, ^b $p = .09$

Changes across time within Dutch and Belgian traditional and small-scale settings

It was also examined whether there were any changes over time in the different quality of life subscales in traditional and small-scale settings in the Netherlands and Belgium. The results of the analyses are presented in Table 4. For the Dutch sample, it was found that the mean scores on the quality of life subscales 'social relations' and 'positive affect' remained stable over time in traditional settings, but decreased in small-scale settings. Nevertheless, after a year the means on these scales were still higher in small-scale settings than in traditional settings. Moreover, the mean quality of life score on 'caregiver relation' and 'negative affect' decreased significantly over time in Dutch traditional settings, whereas it remained stable in Dutch small-scale settings. In addition, 'negative affect' increased in traditional settings but not in small-scale settings.

In the Belgian sample, the pattern of results is again somewhat different. For example, it was found that, over time, residents felt more at home in traditional settings, whereas in small-scale settings the mean score on this quality of life measure remained stable. It was also found that, over time, residents in small-scale settings achieved significantly lower quality of life scores on the aspect 'restless behaviour' whereas no such decrease was found for traditional settings. Moreover, the mean scores on 'having something to do' and 'social relations' decreased over time in small-scale settings, but not in traditional settings.

Table 4. Relationship between time of measurement and quality of life in traditional and small-scale settings in the Netherlands and Belgium: Coefficients and estimated mean scores

			Coefficient	Baseline	T1	T2
Caregiver Relation	Netherlands	Traditional	-1.31 ^{a***}	15.53	14.22	12.90
		Small-scale	0.17	14.52	14.69	14.86
	Belgium	Traditional	0.92	13.56	14.47	15.39
		Small-scale	0.01	14.79	14.80	14.81
Positive Affect	Netherlands	Traditional	-0.15	10.99	10.84	10.69
		Small-scale	-0.81 ^{b*}	14.80	13.99	13.18
	Belgium	Traditional	-0.43	12.18	11.76	11.33
		Small-scale	-0.73	13.40	12.41	11.68
Negative Affect	Netherlands	Traditional	-0.75 ^{c*}	6.65	5.90	5.15
		Small-scale	0.20	5.35	5.55	5.76
	Belgium	Traditional	0.18	4.45	4.63	4.81
		Small-scale	-0.30	6.24	5.94	5.64
Positive Self-Image	Netherlands	Traditional	0.23	7.22	7.45	7.67
		Small-scale	0.06	7.55	7.61	7.67
	Belgium	Traditional	0.04	6.21	6.25	6.29
		Small-scale	0.14	6.33	6.47	6.60
Social Relations	Netherlands	Traditional	-0.06	8.36	8.29	8.23
		Small-scale	-0.90 ^{d**}	11.72	10.82	9.92
	Belgium	Traditional	-0.58	10.79	10.21	9.63
		Small-scale	-1.03 ^{***}	11.18	10.15	9.11
Social Isolation	Netherlands	Traditional	-0.43	6.73	6.30	5.87
		Small-scale	-0.11	6.23	6.13	6.02
	Belgium	Traditional	0.26	5.31	5.57	5.83
		Small-scale	0.07	5.77	5.84	5.91
Feeling at Home	Netherlands	Traditional	0.09	10.15	10.24	10.33
		Small-scale	0.30	9.31	9.61	9.91
	Belgium	Traditional	0.85 ^{f**}	8.32	9.17	10.02
		Small-scale	0.36	9.08	9.44	9.80
Restless Behaviour	Netherlands	Traditional	-0.85	5.41	4.56	3.71
		Small-scale	-0.06	5.14	5.08	5.03
	Belgium	Traditional	-0.24	4.46	4.22	3.98
		Small-scale	-0.91 ^{g*}	4.56	3.65	2.74
Having Something to Do	Netherlands	Traditional	-0.27	1.15	0.88	0.62
		Small-scale	-0.21	2.62	2.41	2.20
	Belgium	Traditional	-0.12	1.67	1.55	1.43
		Small-scale	-0.38 ^{h*}	2.41	2.03	1.66

Note: At level 1, the model for these analyses was: $y_{ij} = \pi_{0ij} + \pi_{1ij}(\text{Time})_{ij} + \epsilon_{ij}$. In this model, π_{1ij} represents the relationship between time of measurement (at baseline, after six months, and after a year) and a quality of life measure. At level 2, no predictors were entered. At level 3, the following equation examined differences in the Time slope between traditional and small-scale settings in the Netherlands and Belgium: $B_{10j} = \gamma_{101}(\text{BSmall})_j + \gamma_{102}(\text{BReg})_j + \gamma_{103}(\text{NSmall})_j + \gamma_{104}(\text{NReg})_j + u_{10j}$.

*** $p < .001$ ** $p < .01$ * $p < .05$, ^a $p = .000$, ^b $p = .017$, ^c $p = .032$, ^d $p = .001$, ^e $p = .002$, ^f $p = .008$, ^g $p = .043$, ^h $p = .018$

Discussion

This study examined the prevailing view that residents with dementia living in small-scale settings in the Netherlands and Belgium score better on domains of quality of life compared to those in traditional care settings. Within the countries, analyses were conducted to test whether the prevailing view on small-scale living is correct. We expected that residents living in these types of facilities would differ on some, but not on all of these quality of life domains, due to reduced levels of behavioural problems and depression, a lower use of behavioural interventions (i.e. use of restraints and actual use of psychotropic medication), as well as higher levels of social interaction (i.e. social engagement and visiting frequency of relatives).

In line with previous studies [9, 13, 17], our findings suggest that small-scale living settings may have some beneficial effects on residents. In the Dutch sample, residents in small-scale settings had higher scores on 'social relations', 'positive affect', and 'having something to do' than residents in traditional settings. Moreover, mean scores on 'caregiver relation' and 'negative affect' remained stable over time among residents in small-scale settings, but decreased in traditional settings. In the Belgian sample, fewer differences were found between traditional and small-scale settings. Nevertheless, residents in small-scale settings were reported to experience less 'negative affect' than in traditional settings. These differences could be explained by differences between traditional and small-scale settings in depressive symptoms. Other differences between traditional and small-scale living facilities could not be explained, however, by differences in cognitive impairment, activities of daily living, behavioural problems, depression, use of restraints, actual use of psychotropic medication, social engagement or visits from family.

Although other studies on small-scale living do not extensively discuss results in traditional settings, it is important to mention that this study also found some beneficial effects of living in a traditional setting on residents with dementia. In Belgium, scores on the QoL subscale 'feeling at home' increased over time in traditional settings, whereas in other settings the scores remained stable. Furthermore, scores on the subscales 'social relations' and 'positive affect' remained stable in traditional settings, whereas they decreased in small-scale settings in the Netherlands. However, after a year, the scores were still higher in small-scale, compared to traditional settings. It was also found that in all settings, except Belgian small-scale settings, the scores of residents on the QoL subscale 'restless behaviour' remained stable over time. In the Belgian small-scale settings, the scores on this subscale decreased significantly.

There were some limitations in this study. As self-reporting by residents with dementia is difficult, data had to be gathered through proxy reports from professional caregivers. The disadvantage of proxy ratings is that they filter a subjective measure through the opinion of another person. Nevertheless, observation by one or more professional caregivers is considered to be the best, most reliable and valid alternative method [44].

Although there is always a possibility that participants had knowledge of other participating units, we believe that this was kept to a minimum because nurses and nursing assistants worked only in one unit and assessed residents they knew very well on an individual level using a multitude of different scales. Moreover, they filled in the questionnaires together and were trained to fill in the booklet with scales correctly.

Another possible limitation is that, due to ethical and practical considerations, the residents in the study could not be randomly assigned to conditions. The study was therefore conducted as a quasi-experimental design in actual real-life care settings, with differences

between individual participants, long-term care settings and countries. Although we controlled for relevant background variables, there is always a possibility that institutions may have differed on other variables as well.

Despite these limitations, the present results are of importance for future research on the diversity of care settings for older people with dementia in general. Future research should evaluate the added value of small-scale living compared to traditional settings in order to provide an insight into the whole concept of quality of care for residents with dementia, including the perspectives of family and professional caregivers. The current findings may have implications for care policy and practice worldwide. For example, developing and investing in differentiated types of residential care facilities for people with dementia, according to their own wishes and preferences, could prove to be beneficial for their quality of life in general. Moreover, because this study shows that quality of life is not based on the scale and design of the environment in long-term care settings alone, the focus of nursing home research needs to shift towards examining the effects of both the quality and content of the care provided. Lastly, we would like to note that, to be able to evaluate quality of life for individual residents, as well as the quality and content of care, it is important to incorporate the different perspectives within the 'care giving triangle' between residents, family and professional caregivers.

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**Functional status, behaviour
and social interaction of
residents with dementia living
in small-scale and traditional
long-term care settings in the
Netherlands and Belgium**

CHAPTER 4

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Abstract

Study Background

The aim of this study was to examine how residents with dementia living in small-scale and traditional long-term care settings in the Netherlands and Belgium differ in terms of activities of daily living, behavioural problems, depression, use of restraints, psychotropic medication, social engagement and visiting frequency of relatives.

Methods

The study had a longitudinal design with a time interval of one year. Participants were 179 residents with dementia in Dutch small-scale (N=51) and traditional (N=51), and Belgian small-scale (N=47) and traditional (N=30) care settings. Data were obtained by professional caregivers using validated observational measurement instruments.

Results

Results show few differences between residents in small-scale and traditional settings in the two countries. In the Netherlands, residents in small-scale settings were more socially engaged and better able to perform activities of daily living compared to residents in traditional settings. In Belgium, residents in small-scale settings were also better able to perform activities of daily living, and showed fewer depressive symptoms than residents in traditional settings. Over time, activities of daily living decreased in residents of both small-scale and traditional settings in both countries. Social engagement also decreased in both countries among residents in small-scale settings but remained stable among residents in traditional settings. Furthermore, behavioural problems decreased over time in traditional settings in both countries, but remained stable in small-scale settings.

Conclusions

Relatively few differences were found between small-scale and traditional settings in the two countries as regards residents' social engagement, activities of daily living, depression and behavioural problems. The assumption made in policy and practice, however, is that living in small-scale settings is better for residents with dementia. To better understand why small-scale settings may not always be more beneficial for residents compared to traditional settings, future research should examine the patterns found in this study in more depth.

Introduction

Some 4.6 million people are diagnosed with dementia throughout the world every year, and the expectation is that by 2030 there will be around 63 million people suffering from dementia worldwide [1]. The progression of the disease differs for every individual with dementia, as does the care trajectory for individual sufferers [2]. People usually prefer home-based care over residential care, but for a substantial number of people in the later stages of dementia, staying at home is no longer possible [3] and transfer to residential care is inevitable [4]. As the number of people with dementia is expected to increase, the demand for residential care will also increase.

Organizations providing residential care for people with dementia face the challenge of meeting this growing demand. Over the last decade, the emphasis in institutional dementia care has shifted towards a more home-like and person-centred approach, with more attention for the preferences of individual residents [5]. Whereas in traditional residential settings, the institutional rhythm is mainly determined by the logistics of medical and nursing care [6].

This new approach aims to enable residents to continue the way of living they were used to and to offer them possibilities for social participation. For this reason, in many countries with a long history of nursing home care, traditional, large-scale nursing homes are currently trying to transform their hospital-like care environments into more normalized and person-centred settings. In addition, many newly developed long-term care settings for older persons with dementia are specifically trying to put this new approach into practice by creating small-scale living facilities [7-9].

An itemized overview of the key differences between typical small-scale and traditional long-term care settings is presented in Table 1.

Table 1. Itemized summary of the key differences between small-scale and traditional long-term care settings

Small-scale long-term care settings	Traditional long-term care settings
Home-like, holistic and person-centred approach ^a	Medical- and nursing based approach
Focus on the normalization of living and maintenance of one's original lifestyle	Focus on care
Additional focus on client interaction	Main focus on basic technical care giving skills
Participation in daily activities is stimulated	Staff performs most daily activities
Groups are relatively small (usually 6 - 8)	Groups are larger (usually >20)
Day schedule according to resident's preferences	Routine institution directed day schedule
Environment is familiar and home-like	Environment is hospital-like
Number of caregivers is smaller	Number of caregivers is larger
Staff wears no uniforms	Staff wears uniforms
Staff tasks are integrated ^b	Staff tasks are more differentiated ^b
More individual decision making by staff members	More collective decision making by staff members

^a This means that the vision of small-scale living is to provide care that fits into the lifestyle that people were used to in their own home (home-like), that encompasses all aspects of people's needs, psychological, physical and social should be taken into account and seen as a whole (holistic) and of which the focus is on the needs of the individual resident (person-centred).

^b In traditional long-term care settings staff members usually carry out a specific part of the care tasks. Tasks are thus differentiated between staff members. In small-scale long-term care settings staff members carry out all different tasks, such as cooking and social activities, as well as technical care giving tasks. Thus in these settings there is almost no task specialization.

In today's residential care practice, it is commonly assumed that small-scale, home-like environments are the preferred and best way to offer care to residents with dementia [10, 11]. However, scientific research testing this assumption has thus far only been conducted on a small scale. Moreover, studies that have compared residential living conditions in small-scale and traditional settings have generally found mixed results and have not provided solid support for this assumption [7, 12, 13].

Furthermore, studies comparing traditional and small-scale living facilities have primarily focused on quality of life of the residents as the primary outcome [7, 12, 14, 15]. Although quality of life of residents is a very important outcome parameter in the assessment of a care programme [16], it is also possible that residents of small-scale and traditional living facilities differ on other important outcome aspects, such as activities of daily living (ADL), behaviour and social interaction of persons with dementia. Yet, only a few researchers have compared traditional and small-scale care settings on one or more of these aspects [17-19]. An integral array of aspects influencing residents with dementia, incorporating for example behavioural problems, use of restraints and visits from family members, has to date not been examined in a single study design.

The aim of the present study was to fill this gap by examining the effect of living in a small-scale or traditional long-term care setting on functional status, behaviour and social interaction of people with dementia. More specifically, we examined whether and how residents in small-scale and traditional settings differ in functional status (i.e. the level of dependency in activities of daily living) and also in terms of behavioural characteristics (i.e. behavioural problems and depression), behavioural interventions (i.e. use of restraints and psychotropic medication) and social interaction (i.e. social engagement and visits from family). We also examined whether and how residents' scores on these aspects changed over time (one year). This was done to rule out the possibility that findings might represent only a random indication at a specific moment in time. Furthermore, this allowed us to examine whether residents in small-scale settings would remain more stable over time in terms of their physical, psychological, and social functioning compared to residents in traditional settings. Data were collected among residents of small-scale and traditional settings in the Netherlands and in Belgium.

In this study, we expect that residents in small-scale living settings will show less decline in terms of their *functional status* compared to residents in traditional settings [12, 18], in particular because small-scale settings offer residents more opportunities to perform *activities of daily living* themselves. There is evidence that this positively affects the independence of older people with dementia [20, 21].

Mild to severe behavioural problems are present in about 64% of all cases of dementia [22]. We have no clear hypotheses about whether residents in small-scale settings differ from residents in traditional settings in terms of *behavioural problems*, because previous research has found no differences between units on this aspect [12, 14, 17].

One third of all people diagnosed with dementia also experience *depressive symptoms* [23] which have a very marked negative influence [24, 25]. Nevertheless, it is unclear whether residents in small-scale and traditional settings differ in terms of depressive symptoms. Whereas some studies have found that residents in small-scale living settings reported fewer depressive symptoms [19] and had better emotional health [7] compared to residents in traditional nursing home care, a recent study in the Netherlands found no differences between small-scale living and traditional long-term care in terms of depression [14].

There is an ongoing discussion in the field of dementia care about the use of *behavioural interventions*, involving the need for and safety of the *use of restraints* and *psychotropic*

medication. In long-term care settings it is still common practice for an array of *restraints* to be used. Research on the efficiency of restraints in nursing homes has, however, shown that restrictive devices can often be removed without negative consequences and that this is associated with positive patient outcomes [26]. Despite inconsistent results, we hypothesize that the *use of restraints* will be lower in small-scale living facilities compared to traditional units. Also administering psychotropic drugs to residents with dementia to control their neuropsychiatric symptoms is still common practice, but whether they are beneficial in all cases is questionable [27]. Prescription of *psychotropic medication* is expected to be lower in small-scale settings because the majority of studies have confirmed that psychotropic medication is less often prescribed for residents in small-scale settings [12, 14].

Although *social engagement* is likely to change for a person with dementia (i.e., making contact often becomes more difficult as the disease progresses), they may actually benefit from targeted social interaction [28]. Regular *visits from family and friends* may temporarily reduce agitation [29] and visits in general have been shown to positively affect behavioural problems [30]. We expect residents in small-scale settings to be more socially engaged than residents in traditional dementia care units. In this regard, studies on small-scale living have also found that residents in small-scale care facilities are more frequently engaged in verbal communication [19], show more interest in their surroundings [18] and have better relationships with other residents and caregivers in the facility compared to traditional care settings [7]. One recent study in the Netherlands also found that residents in small-scale living settings were more socially engaged compared to residents living in traditional units [12]. We also expect the *visiting frequency of relatives* to be higher for residents in small-scale living settings compared to those in traditional settings, because small-scale facilities are likely to be more appealing for family members than the hospital-like environment in traditional units.

Setting the scene

This study was conducted in the Netherlands and Belgium. Both countries are welfare states, providing services for everyone in need of long-term care. Although the financing and funding systems of long-term dementia care show similarities in both countries, there are also some differences [10, 31]. Funding of long-term care in the Netherlands is based on a system of Care Severity Packages provided by law (the Exceptional Medical Expenses Act, AWBZ) [32], which are individual budgets paid to institutions to enable them to provide care to their residents [33]. Residents are obliged to make an income-dependent contribution [34]. In Belgium, nursing homes are partly funded by the federal government and partly by the regional authorities. Additionally, residents have to pay a daily fee for food and lodging [35].

Moreover, Belgium has a longer history (since 1978) of small-scale long-term care [11] than the Netherlands (since 1986) [36]. In Dutch small-scale facilities, groups usually comprise six to eight residents [37], whereas in Belgium the number is usually between six and nine [11] and in Belgium the groups are sometimes enlarged to between 12 and 15 residents due to funding issues [11].

Given these and other differences between the two countries, the focus in this study was on within-country comparisons between small-scale and traditional settings, rather than on between-country comparisons (e.g. between small-scale settings in the Netherlands and Belgium). We expected, however, to find a similar pattern of results in the two countries, because of the various similarities in their vision on and organisation of dementia care.

Materials and methods

This study had a longitudinal design, with three measurement moments over a period of one year. Data were gathered at baseline, after six months and after twelve months in traditional and small-scale long-term care settings in the Netherlands and Belgium. The study was part of a larger longitudinal study on the similarities and differences between traditional and small-scale long-term dementia care settings, examining residents, family and professional caregivers in the Netherlands and Belgium [38]. The focus in this study was on functional status, various behavioural characteristics, behavioural interventions, and social interaction.

Sample

Five institutional long-term care organizations, operating four traditional and 12 small-scale units in the south of the Netherlands and the north of Belgium, were approached for the study and were willing to participate. Data were obtained from 179 residents (142 female, 37 male) aged over 65 years with dementia, who had been assessed to be suffering from dementia and in need of residential psychogeriatric care prior to their admission to the long-term care setting. Due to the severity of the disease, all participants in this study were not competent to act for themselves and were under the supervision of a legal representative. The representative is usually a family member; the assignment of responsibilities is controlled by law. Where no family members are available, an independent guardian is appointed by the relevant legal authority. For this study, the legal representatives gave informed consent on behalf of the participants. Data collection took place between December 2007 and January 2010. See Figure 1 for a flow diagram containing participant numbers in each setting at the different measurement moments.

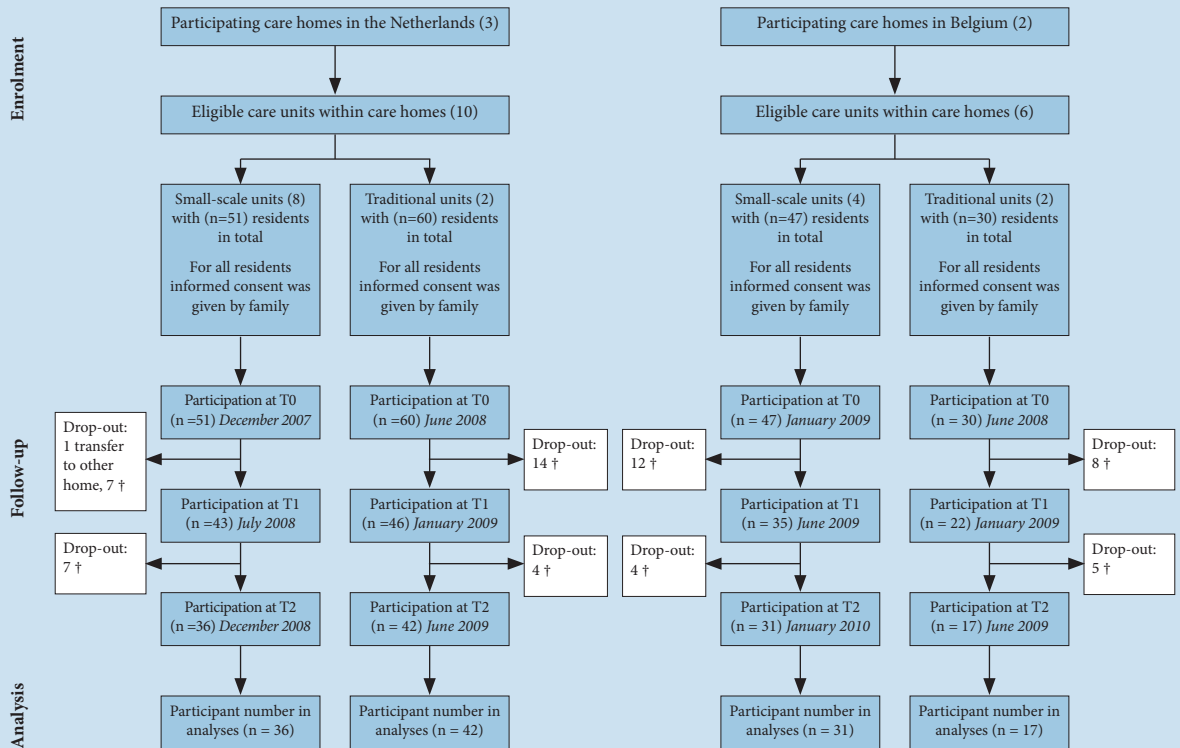
Procedure

We selected validated observational assessment instruments (mainly questionnaires) that had to be filled in by professional caregivers and were applicable to older people in all stages of dementia. This method of observation is considered to be the best, most reliable and valid alternative method of data gathering [39]. Moreover, the instruments used were available in the residents' and professional caregivers' native language (Dutch). All questionnaires were completed at three measurement moments (at baseline, after six months and after 12 months) to examine changes over time and rule out the possibility that the findings might represent only a random indication at a specific moment in time.

Measurements and measurement instruments

To examine *functional status*, the Barthel Index [40] was administered. This index measures independence in ten basic *activities of daily living*, including personal hygiene, using the toilet, getting dressed, walking up and down stairs, bathing, mobility, (in)continence, requiring assistance in transferring from bed to chair, and requiring assistance with feeding. A score of 0 to 2 or 0 to 3 is recorded for each activity. The maximum possible score is 20, ranging from 0 to 4 = completely dependent through to 20 = completely ADL-independent [40]. The Barthel Index was filled in by nurses or nursing assistants who knew the residents very well.

Behavioural problems were assessed using the NPI-NH (Neuropsychiatric Inventory - Nursing Home Version), measuring separate behavioural disorders such as delusions, hallucinations, agitation, phobia, euphoria, apathy, aberrant motor behaviour, sleeping and eating disorders [41]. The NPI-NH gives an insight into the severity, frequency and workload

Figure 1 Flow diagram of participants through the study

of each of the separate behavioural disorders [41]. Behavioural problems were assessed by an independent psychologist interviewing the nurse or nursing assistant.

Depression was measured using the CSDD (Cornell Scale for Depression in Dementia), which has been specifically developed to identify depressive symptoms in older people with dementia [42]. The CSDD incorporates mood, behavioural disorders, physical characteristics of depression and cyclical functions and disorders in cognitive content. The observational scale contains 19 items and ranges from: a = cannot be judged, 0 = absent, 1 = mild, 2 = severe). Scores above 18 indicate a definite major depression [42]. The CSDD was filled in by nurses or nursing assistants who knew the residents very well.

The *use of physical restraints*, being any limitations imposed on an individual's freedom of movement [43], including their number and type, was recorded as absent or present from the personal files of the residents. The range of restraining measures included fixation with belts, small and large bed-belts, (wheel)chair belts, securing the person to the mattress with a sheet, using a fixed table top in a chair, use of bilateral full-enclosure bedrails, and use of sensor mats and infrared sensors (motion alarms) in the bedroom.

The number of different *psychotropic medications* prescribed was taken from the medical files of the residents. Psychotropic medication was divided into three types: sedatives, antidepressants and antipsychotics [44].

Social engagement was measured using the RISE (Revised Index of Social Engagement), which is a subscale taken from the larger Resident Assessment Instrument 2.0 (RAI 2.0) [45]. The Revised Index for Social Engagement (RISE) measures the social involvement of residents with other residents, professional caregivers and relatives. The scale contains eight questions about the social interaction of the resident, indicating whether or not the specific social situation mentioned in the question has occurred over the last seven days. RISE is one of the scales derived from the larger instrument Resident Assessment Instrument 2.0 (RAI 2.0) [45]. The RAI 2.0 is used to assess a variety of factors related to the functioning of residents in care homes [46]. The RISE was filled in by nurses or nursing assistants who knew the residents very well.

The *visiting frequency of relatives* was recorded by a nurse or nursing assistant on a five-point scale ranging from almost every day, once or twice a week, once every two weeks, once a month to less than once a month.

To be able to control for potential differences in basic characteristics, age, sex and cognitive impairment were recorded. Residents with dementia being older or more severely impaired might perform worse on patient outcomes, just due to their impairment, and not due to living in a particular type of care unit. Age and sex were taken from the personal records of the residents. All residents had received a diagnosis of dementia prior to admission to the care facility. The S-MMSE (Standardized Mini Mental State Examination) was administered to each resident to assess the severity of *cognitive impairment* [47, 48]. Residents were asked to answer a series of 11 questions. The maximum possible test score was 30 [48]. This test was performed by an independent psychologist interviewing the residents themselves.

To control for the number of nursing staff available to residents, full-time equivalent data (corrected for the number of residents living in each group) were collected for each care unit.

Analytic strategy

The data gathered had a ‘multilevel data structure’, i.e., observations over time (level 1) were nested within persons (level 2), which were then nested within settings (level 3). For this reason, the data were analyzed using a series of multilevel modeling analyses, using the HLM program [49].

In a first set of analyses, we estimated means for the different outcome measures, and compared these means across the different types of settings in Belgium and the Netherlands. No predictors were entered in the level-1 and level-2 models, and so these models were “totally unconditional”. Differences among the small-scale and traditional settings in the Netherlands and Belgium were examined at level 3 with so-called no-intercept models, and the coefficients that resulted from these analyses represent the mean for each site on a specific measure. In a series of follow-up analyses, these coefficients (mean scores) were compared using ‘tests of fixed effects’ [50, 51]. In these analyses, the means of the traditional and small-scale settings were compared within Belgium and the Netherlands¹.

A second set of analyses examined changes across time in the different outcome measures for small-scale and traditional settings in the Netherlands and Belgium. For this purpose, time of measurement (coded as 0, 1, or 2) was added (uncentered) at level 1. At level 2, no predictors were entered and at level 3, differences in the Time slope across small-scale and traditional settings in the Netherlands and Belgium were again examined with so-called no intercept models.

¹The level 1 model in these analyses was as follows: $y_{ijt} = \pi_{0ij} + e_{ijt}$. In this model, y_{ijt} is an outcome measure (e.g., social engagement) at time t for person i in setting j , π_{0ij} is a random coefficient representing the mean of y for person i in setting j , and e_{ijt} represents the error associated with each measure. The level 2 model was: $\pi_{0ij} = \beta_{0oj} + r_{0ij}$. In this model, β_{0oj} is the mean on an outcome measure in setting j , and r_{0ij} is a random “setting” effect (i.e., the deviation of person i ’s mean from the setting mean). At level 3, the model was: $\beta_{0oj} = \gamma_{000}(\text{BSmall}) + \gamma_{001}(\text{BTrad}) + \gamma_{002}(\text{NSmall}) + \gamma_{003}(\text{NTrad}) + u_{0oj}$. In these models, BSmall, BTrad, NSmall, and NTrad were uncentered dummy-coded variables representing the small-scale or traditional settings in Belgium or the Netherlands.

In this model, the Time slope (B_{10j}) was brought up from level 1 and the resulting coefficients represented the mean slopes for each type of living facility in each country. Effects were modeled as fixed when the random error term was not significant².

Results

Basic characteristics of participants and settings

Table 2 presents descriptive data of residents by country and type of setting. The mean age of the residents in years ranged from 83.99 in Dutch traditional settings to 89.09 in the Belgian traditional settings.

Table 2. Characteristics of residents (N=179) and traditional and small-scale settings in the Netherlands and Belgium

	Netherlands Traditional (A) (2 wards, n=51)	Netherlands Small-scale (B) (8 wards, n=51)	Belgium Traditional (C) (2 wards, n=30)	Belgium Small-scale (D) (4 wards, n=47)
Age in years, M(SD)	83.99 (5.12) ^C	84.50 (5.86) ^C	89.09 (5.67) ^{A, B, D}	84.52 (7.05) ^C
Women (%)	34 (67%)	41 (80%)	25 (83%)	42 (89%)
S-MMSE (0-30) ¹	4.96 (5.59)	7.61 (6.26)	8.10 (8.06)	6.07 (5.57)
FTE ²	19.45	11.95	12.67	13.15
Number of residents per unit, n	30 (2 living rooms with 15 residents)	12 (2 living rooms with 6 residents)	30 (2 living rooms with 15 residents)	30 (2 living rooms with 15 residents)
Available hours of care per capita, in hours per week	23.34	35.85	16.05	16.66

Note: F-tests were conducted and letters are assigned to groups in superscripts indicating significantly different pairs (following Bonferroni correction) at the $p < .01$ level, two-tailed.

¹ Higher scores mean better cognitive skills (S-MMSE).

² FTEs are calculated on the basis of data provided by the nursing homes. A single FTE consists of 36 working hours in the Netherlands and 38 working hours in Belgium. Only nurses and nursing assistants were included (i.e. no medical doctors, physiotherapists, psychologists etc.).

Mean differences in functional status, behavioural characteristics, behavioural interventions and social interaction between small-scale and traditional settings

Table 3 presents an overview of the (unadjusted) mean scores (aggregated over the three measurement moments) on the different measures in traditional and small-scale settings in the Netherlands and Belgium.

It was found that residents in small-scale settings in the Netherlands were reported to be more socially engaged ($p = .004$) and to be more independent in performing activities of daily living ($p < .001$) compared to residents in traditional settings. On the other measures, however, no differences were found between small-scale and traditional settings in the Netherlands. In Belgium, two differences were found between small-scale and traditional settings that reached conventional levels of significance: residents in small-scale settings were somewhat

² In these analyses, the level 1 model was: $y_{ij} = \pi_{0ij} + \pi_{1ij}(\text{Time})_{ij} + e_{ij}$. In this model, π_{ij} represents the relationship between time of measurement (at baseline, after six months, and after one year) and an outcome measure. At level 2, the model was: $\pi_{0ij} = \beta_{00j} + r_{0ij}$. At level 3, the Time slope (β_{10j}) was brought up from level 1 in the following model: $\beta_{10j} = \gamma_{100}(\text{BSmall})_j + \gamma_{101}(\text{BTrad})_j + \gamma_{102}(\text{NSmall})_j + \gamma_{103}(\text{NTrad})_j + u_{10j}$. The resulting coefficients represented the mean slopes for each type of living facility in each country.

more independent in performing activities of daily living ($p = .09$), and were also reported to display fewer depressive symptoms ($p = .09$).

Table 3. Within-country comparisons of means (aggregated across time) for functional status, behavioural characteristics, behavioural interventions and social interaction by type of setting

	The Netherlands		Belgium	
	Traditional	Small-scale	Traditional	Small-scale
Activities of Daily Living (0-20)	4.03	8.15***	5.14	6.97†
Behavioural Problems (0-144)	17.53	21.43	15.75	17.57
Depression (0-38)	8.45	8.37	10.27	8.50†
Use of Restraints (#)	1.11	1.18	1.11	1.16
Prescription of Psychotropic Medication (#)	1.47	1.29	1.68	1.99
Social Engagement (0-8)	2.43	3.69**	2.52	2.71
Visiting Frequency (1-5)	2.27	1.95	2.25	2.07

Note: An asterisk indicates that the mean on a scale in traditional settings is significantly different from the mean in small-scale settings in the same country: *** $p < .001$, ** $p < .01$, † $p < .10$.

A higher score indicates a better ability to perform activities of daily living, more behavioural problems, higher depression, a higher number of absolute restraints and prescribed medications, more social engagement (rate 0-8 activities in the past two weeks) and fewer visits (1 = almost every day, 2 = once or twice a week, 3 = once every two weeks, 4 = once a month or 5 = less than once a month).

In an additional set of analyses, we controlled for relevant background variables (i.e., sex, age, cognitive impairment, and FTE nursing staff). This did not change the pattern of results meaningfully, however, except that the p -value for the difference between small-scale and traditional settings in Belgium in independence in activities of daily living when controlling for cognitive impairment decreased from ($p = .09$) to ($p = .02$).

Changes across time within Dutch and Belgian small-scale and traditional settings

The results from the analyses assessing changes across time are presented in Table 4.

As can be deduced from this table, the pattern of results was roughly similar for the Dutch and Belgian samples. At baseline, social engagement was relatively high in small-scale settings in both countries but decreased over time ($ps < .016$)³, and at Time 2 social engagement scores in small-scale and traditional settings were comparable. Independence in activities of daily living decreased in both traditional and small-scale settings in Belgium and the Netherlands ($ps < .006$), but were still meaningfully higher at Time 2 in small-scale settings than in traditional wards. It was also found, however, that the use of psychotropic medication increased in small-scale settings in both the Netherlands and Belgium ($ps < .023$). Furthermore, it was found that mean scores on behavioural problems decreased over time in traditional wards in the Netherlands and Belgium, but not in small-scale settings ($ps < .024$). In the Belgian sample, the use of restraints also increased over time in small-scale settings ($p = .005$), as did the visiting frequency of relatives ($p = .046$).

³ps stands for p -value in plural, for example ($ps < .016$) means that all found p -values of the indicated effect were below .016.

Table 4. Relationship between time of measurement of functional status, behavioural characteristics, behavioural interventions and social interaction in traditional and small-scale settings in the Netherlands and Belgium: coefficients and estimated mean scores

Measure (Range)		Coefficients	Baseline	Time 1	Time 2
<i>Activities of Daily Living (0-20)</i>					
Netherlands	Traditional	-1.26***	5.15	3.89	2.63
	Small-scale	-0.81**	8.82	8.01	7.20
Belgium	Traditional	-1.27**	6.02	4.75	3.48
	Small-scale	-1.72***	8.28	6.56	4.84
<i>Behavioural Problems (0-144)</i>					
Netherlands	Traditional	-3.72***	20.84	17.12	13.40
	Small-scale	-2.28	23.20	20.92	18.64
Belgium	Traditional	-4.52***	19.21	14.69	10.17
	Small-scale	0.10	17.50	17.60	17.70
<i>Depression (0-38)</i>					
Netherlands	Traditional	0.71	7.82	8.53	9.24
	Small-scale	-0.26	8.60	8.34	8.08
Belgium	Traditional	-1.16	11.05	9.89	8.73
	Small-scale	1.03†	7.72	8.75	9.78
<i>Use of Restraints (#)</i>					
Netherlands	Traditional	0.10	1.03	1.13	1.23
	Small-scale	0.04	1.14	1.18	1.22
Belgium	Traditional	0.09	1.05	1.14	1.23
	Small-scale	0.23**	0.99	1.22	1.45
<i>Prescription of Psychotropic Medication (#)</i>					
Netherlands	Traditional	-0.05	1.51	1.46	1.41
	Small-scale	0.15**	1.16	1.31	1.46
Belgium	Traditional	-0.02	1.70	1.68	1.66
	Small-scale	0.20**	1.84	2.04	2.24
<i>Social Engagement (0-8)</i>					
Netherlands	Traditional	-0.13	2.56	2.43	2.30
	Small-scale	-0.67**	4.28	3.61	2.94
Belgium	Traditional	-0.01	2.54	2.53	2.52
	Small-scale	-0.64*	3.20	2.56	1.92
<i>Visiting Frequency (1-5)</i>					
Netherlands	Traditional	0.02	2.24	2.26	2.28
	Small-scale	0.04	1.91	1.95	1.99
Belgium	Traditional	0.14	2.15	2.29	2.43
	Small-scale	0.14*	1.97	2.11	2.25

A higher score indicates a better ability to perform activities of daily living, more behavioural problems, higher depression, a higher number of absolute restraints and prescribed medications, more social engagement (rate 0-8 activities in the past two weeks) and fewer visits (1 = almost every day, 2 = once or twice a week, 3 = once every two weeks, 4 = once a month or 5 = less than once a month). Within-country significantly different slopes are indicated by asterisks: *** $p < .001$, ** $p < .01$, * $p < .05$ † $p < .10$.

In an additional set of analyses, we controlled for relevant background variables (age, sex, cognitive impairment, group size and FTE nursing staff). This did not, however, change the pattern of results meaningfully.

Discussion

This study examined whether residents in small-scale settings show, compared to residents in traditional settings, less decline in functional status, display different levels of behavioural problems, have different levels of depressive symptoms, are more socially engaged and receive more visits from family. Moreover, it was also examined whether fewer restraints were employed and whether less medication was prescribed in small-scale settings. Contrary to our expectations, it was found that residents in small-scale settings differed on only a few aspects from residents in traditional settings. In the Netherlands, residents in small-scale settings were more independent in activities of daily living and were also more socially engaged compared to residents in traditional settings. In Belgium, residents in small-scale settings were found to be more independent in activities of daily living and were also reported to display fewer depressive symptoms. The results in the Dutch and Belgian settings on independence in ADL resemble the results of two recent studies in the Netherlands [12, 37] and are in line with our expectations, because residents in small-scale living settings are encouraged to perform activities themselves (as long as possible) and have more opportunities to participate socially. Moreover, a difference was found in the Belgian settings on depression, where residents in small-scale settings displayed fewer depressive symptoms. This finding is in line with some other previous studies that found fewer depressive symptoms and better emotional health in small-scale settings [7, 19]. On the other dimensions, however, no differences were found between small-scale and traditional settings. Looking at changes across time, the results were roughly similar in the Netherlands and Belgium. Nevertheless, some interesting differences between residents in small-scale and traditional settings appeared. At baseline, social engagement of residents was relatively high in small-scale settings in both countries but decreased over time, while the level of engagement in traditional settings remained the same. This is interesting, because other studies comparing small-scale and traditional settings found evidence that residents in small-scale settings are generally more socially engaged [7, 14, 18, 19]. Furthermore, activities of daily living decreased over time in both traditional and small-scale settings in both countries. However, they were still meaningfully higher after one year in small-scale compared to traditional settings. The use of psychotropic medication increased in small-scale settings in the Netherlands and Belgium, whereas it remained the same in traditional settings. Because these results did not fit in with our expectations, we checked whether in daily practice medication prescription protocols differed between small-scale and traditional long-term care settings. We found that the protocols indeed did not differ much, which might be a possible explanation for finding no differences in medication prescription.

Behavioural problems remained stable in small-scale settings, whereas in traditional settings the number of behavioural problems displayed by residents decreased over time. It might be that the differences in patterns can be explained by the more structured living environment and fixed daily rhythm in traditional settings. However, on the basis of our data we cannot draw definite conclusions. Therefore, these differences deserve more research attention.

All in all, this study demonstrates that small-scale settings seem to be positively related to residents' social engagement, activities of daily living, depression and visiting frequency, whereas traditional settings seem to be positively related to behavioural problems. Nevertheless, this study also has some limitations. Due to ethical considerations, a randomised controlled trial design was impossible. Although the participating settings were selected based on their similar view of caregiving, the small-scale and traditional settings in the two countries might possibly differ on aspects that were not taken into account, such as different nursing methods, handling of behavioural problems, staff attitudes, design of the environment, culture, atmosphere and means of family participation in care. The settings are real-life care settings and have specific characteristics that may vary within and between countries.

In daily long-term care practice, it is still assumed that living in small-scale settings is more beneficial for residents with dementia, and this vision also dominates policy and practice. However, the findings of this study do not provide unconditional support for this assumption, and future studies should examine this in more detail. For example, qualitative studies might provide a better understanding of the patterns that were found in this study. Moreover, future research in this field should focus more on the quality and content of the care provided.

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**Family caregiver perspectives
on social relations of elderly
residents with dementia in
small-scale versus traditional
long-term care settings in the
Netherlands and Belgium**

CHAPTER

5

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Abstract

Aim

To provide insight into family caregiver perspectives on social relations within the 'caring triangle' between family caregiver, professional caregiver and elderly resident with dementia. Results were compared between traditional versus small-scale long-term care settings in the Netherlands and Belgium.

Background

Residential dementia care is shifting towards a more holistic and person-centred approach. Until now little is known about family caregiver perspectives.

Design

The study followed a quasi-experimental longitudinal design.

Method

This study was part of a larger research project focusing on the quality of life of residents with dementia in traditional and small-scale settings ($n = 179$). This study focused on family caregivers related to these residents ($n = 64$). They filled in a questionnaire containing 25 items (baseline and after 12 months) related to their perspectives on the interaction within the 'caring triangle'. Analyses were performed using mixed models and logistic regression.

Results

Compared to traditional settings, family caregivers of relatives with dementia living in small-scale settings had more contact with the professional caregivers, were more satisfied with this contact and felt that staff paid more attention to their feelings as family members. They also reported that staff showed better listening skills towards the residents. Furthermore, compared to those in Belgium, family caregivers in the Netherlands perceived staff to be less hurried and more accepting of help from family and felt that staff more often takes the resident seriously.

Conclusion

In the move towards more person-centred care for residents with dementia, this study finds preliminary evidence for the importance of integrating the family perspective.

Introduction

For decades, traditional long-term residential dementia care has been based on an institutionalised medical and nursing approach, where residents live in relatively large groups, the environment is hospital-like and a large number of different professional caregivers perform differentiated tasks [1]. Over the last decade, this approach has been criticised, among other things because of the rigid organization, the hospital-like culture and the mainly supply oriented approach towards the care receiver [2]. It has been argued that the emphasis in dementia care should move towards a person-centred approach, to create an environment with a better balance between living, well-being and care [2, 3]. This has inspired care providers in several countries to move towards shaping residential care settings more as a smaller-scale, home-like and familiar environment [4-6]. Although there is no widely accepted conceptual definition, these small-scale living facilities share some essential characteristics in their vision on care and in their care practice. In small-scale living facilities, residents live in relatively smaller groups, ranging from six to 16 persons (in Belgium), compared to traditional wards of 20 residents or more. Residents are encouraged to maintain the life habits, activities and hobbies they performed at home and to participate in household activities for as long as possible. The number of professional caregivers is relatively small in small-scale living facilities, and tasks are integrated and less differentiated compared to traditional wards. It is claimed that the normalised environment, which ideally is as home-like as possible, in conjunction with a caring environment focusing on participation in daily activities and supporting relationships, contributes to a residential setting which is as normal as possible and is therefore beneficial for residents [7-10].

Persons with dementia usually prefer home care provided by family and professional caregivers over residential care [11]. Dementia caregiving may provide family and professional caregivers with satisfaction [12, 13], but it can also be burdensome [14] and can even cause depression [15]. The unpredictable disease process of dementia is associated with growing functional, cognitive and behavioural decline, as well as increasing care demands [16]. This often leads to a situation where admission of the person with dementia to a residential care environment becomes inevitable [11]. The transition to a long-term care setting is an emotional period both for the elderly person with dementia and for the family [17], adversely affecting their health and well-being [18]. The family system is very important in this context. Research highlights a crucial need for long-term care facilities to support families, as well as the person with dementia, through the transition to a different care environment [19].

Although the focus of research in small-scale living facilities is usually on residents (e.g. [6, 8, 9]), some studies have also paid attention to the experiences of family caregivers. Studies to date have found varying results, either that family caregivers in small-scale living facilities experience less or the same degree of burden and are more satisfied with the performance of staff compared to family caregivers in traditional long-term care settings [6, 20, 21], or finding no differences for family caregivers between traditional and small-scale long-term care settings [22]. However, these studies mainly focused on psychopathology and burden or level of caregiver competence, with little attention for the relational aspects of being a relative of a person with dementia and the positive aspects of being a caregiver. Therefore, this study focused on the importance of social relations and the positive and negative experiences of family caregivers.

When a relative with dementia is admitted to a long-term care facility, a new 'caregiving triangle' is established; the family caregiver, the professional caregivers of the facility

and the resident with dementia inevitably have to communicate because they are partners in care. The aim of this study was to provide an insight into family caregiver perspectives on the interactions occurring between family caregiver, professional caregiver and elderly resident. Similarities and differences in these perspectives between traditional and small-scale care units and between the Netherlands and Belgium were also examined. Professional caregivers in small-scale settings work in a smaller care team with more emphasis on integrative working. It can, therefore, be assumed that in these facilities, family caregivers and their relatives with dementia will come into more intense contact with fewer professionals, who may know the persons with dementia and their family members relatively better compared to traditional nursing home settings. As a consequence of these characteristics, the hypothesis of this study is that social relations between the family, the resident and the professional caregiver are possibly more intensive in small-scale living facilities than in larger, traditional nursing homes, overall resulting in (among others) more satisfaction of family caregivers.

Three research questions were formulated. The questions deal with the family member's viewpoint on the relational nature of the 'caregiving triangle'. What is the family caregiver perspective in traditional versus small-scale long-term care settings in the Netherlands and Belgium on:

- 1 the interaction between family caregiver and resident?
- 2 the interaction between professional caregiver and resident?
- 3 the interaction between family caregiver and professional caregiver?

Methods

Design

The study had a quasi-experimental design with two measurement moments and was conducted in both traditional and small-scale long-term care settings in the Netherlands and Belgium. Moreover, this study is part of a larger study investigating the similarities and differences between traditional and small-scale long-term care settings for elderly residents with dementia from different perspectives, such as the resident and the family and the professional caregiver. This main study followed a quantitative methodology. A quantitative approach was, therefore, also adopted in the current study, making comparisons between types of units and countries possible and rendering cross-analysis between the studies more feasible. Two measurement moments were used to avoid the possibility of acquiring only a random indication at a given moment in time. In addition, the study was conducted in two countries to provide the possibility of examining whether living in a small-scale care facility in a certain country, whilst having the same underlying explicit small-scale care vision, results in similar or different patterns in outcomes. The choice of the Netherlands and Belgium as the two countries was based on the existence of a comparable manifestation of small-scale living in these countries, while their geographical proximity and the fact that they share the same native language (Dutch) were advantages for data collection. Although the vision of small-scale living is similar in the Netherlands and Belgium, there are also some differences. In the Netherlands, there are more professional caregivers taking care of fewer residents compared to Belgium [9, 23], management of the disease is more multidisciplinary, and small-scale living is more rapidly becoming a widespread residential model for persons with dementia [24]. Moreover, in Belgium, there is less in the way of national policy to encourage small-scale group living and funding

is problematic. As a consequence, the number of initiatives is smaller in Belgium than in the Netherlands [9, 25].

Sample

As mentioned before, this study was part of a larger study, in which 179 elderly residents with dementia, aged over 65 years, living in traditional or small-scale long-term care settings in the Netherlands and Belgium were selected to participate. Five long-term care settings in the south of the Netherlands and in the north of Belgium, all of which had pre-existing collaboration arrangements with the university, were approached for the study and were willing to participate. Family members listed as 'primary caregivers' of each of the 179 residents participating in the larger study were invited to participate by sending them the questionnaire at baseline and after 12 months.

Ethical Issues

The complete trial was registered under trial number: Current Controlled Trials IS-RCTN23772945. The ethics committee at care organisation De Wever, Tilburg, gave its approval for the complete trial in September 2008. The family members of the residents received an information brochure containing information on all aspects of the research at the start of the project. Their participation in the study was voluntary and they were informed that they could end their participation in the study at any time. The privacy of the participating family members was protected and all data were analysed anonymously.

Instrument

A questionnaire containing 25 items, that was previously used in a study on perspectives of family caregivers [26] was also used for this study and sent to the family caregivers at baseline and after 12 months. Items were ascribed to the three research questions: family perspective on interaction between family caregiver and resident (six items); on interaction between professional caregiver and resident (eight items); and on interaction between family and professional caregiver (11 items). The items are shown in Tables 3 and 4.

Statistical analysis

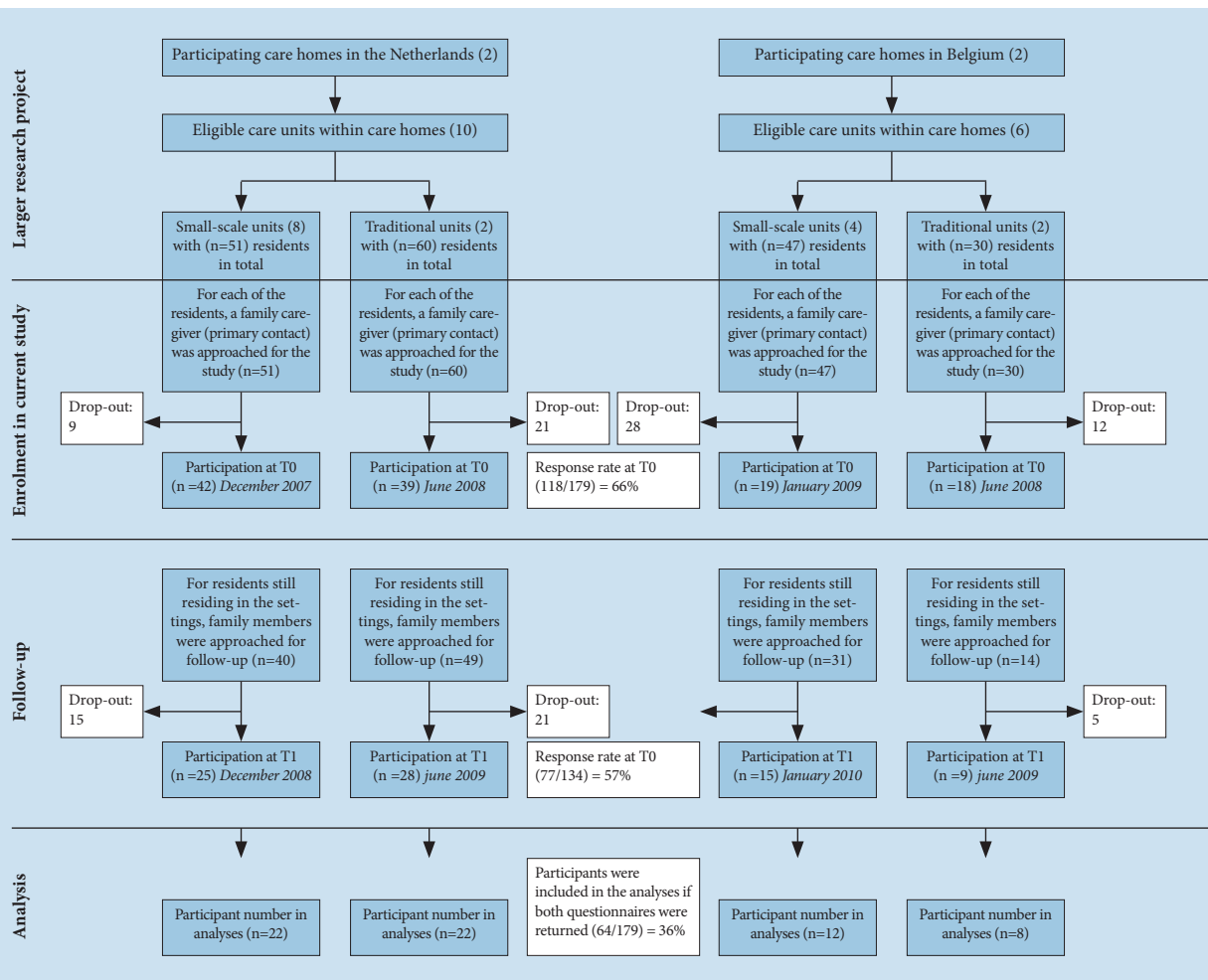
To examine the relationship between the items in the questionnaire, a factor analysis was conducted for the total sample, as well as for each of the four groups separately; traditional and small-scale settings in the Netherlands, and traditional and small-scale settings in Belgium. Principal component analysis did not yield factors with explanatory power, and the items in the questionnaire were therefore analysed separately within the context of the three research questions.

Three sets of analyses systematically examined the items ascribed to the three sections of the 'caregiving triangle' for differences between settings, countries and measurement moments. Patterns in scores on continuous items were examined using the mixed models procedure in PASW Statistics 17 ©, allowing for inclusion of repeated measurements of the same subjects, whereas patterns in scores on dichotomous items were analyzed using logistic regression in PASW Statistics 17 ©, because of the binary nature of the dependent variables. In both methods, the variables type of setting, country and measurement moment were included in the model simultaneously. As a result, the estimated coefficients represent the unique effects on the dependent variable, keeping the other factors stable. In all analyses, relevant background variables (sex and relationship with the resident), were also included, to test whether they influenced the results.

Results

A flow diagram of participants through the study can be found in Figure 1.

Figure 1. Flow diagram of participants through the study



The final experimental group consisted of 44 family caregivers of residents with dementia living in four small-scale group living facilities (in the north of Belgium and the south of the Netherlands). The control group consisted of 20 family caregivers of residents with dementia living in two traditional nursing homes (in the north of Belgium and the south of the Netherlands). In Table 1, characteristics of participating family caregivers are presented. They were mainly children of elderly residents with dementia and an almost equal number of men and women participated.

Table 1. Characteristics of participating family caregivers

	Netherlands Traditional (2 units, n=22)	Netherlands Small-scale (8 units, n=22)	Belgium Traditional (2 units, n=8)	Belgium Small-scale (4 units, n=12)
Women (%)	13 (59.1%)	12 (54.5%)	4 (50.0%)	6 (50.0%)
Relationship to resident				
Child	12 (54.6%)	18 (81.8%)	3 (37.5%)	8 (66.7%)
Spouse	3 (13.6%)	2 (9.1%)	1 (12.5%)	3 (25.0%)
Other*	7 (31.8%)	2 (9.1%)	4 (50.5%)	1 (8.3%)

*Note: category includes sibling, friend and other legal representative.

Table 2. Data related to visits of family caregivers

Question	Answering Range	Frequency N (%)
How often do you visit your family member?	Multiple times each half year	1 (1.6%)
	Once every month	4 (6.3%)
	Multiple times each month	5 (7.8%)
	Once every week	18 (28.1%)
	Multiple times each week	26 (40.6%)
	Once a day	6 (9.4%)
	Multiple times each day	4 (6.3%)
Were you invited to a meeting with staff within 6 weeks after admission?	Yes, within 6 weeks	27 (42.2%)
	Yes, but not within 6 weeks	17 (26.6%)
	No, not invited	12 (18.8%)
	I don't remember	7 (10.9%)
Were you ever invited to a meeting with staff, after the initial meeting upon admission?	Yes, every 6 months	14 (21.9%)
	Yes, but not every 6 months	18 (28.1%)
	No, not invited	24 (37.5%)
	I don't remember	6 (9.4%)
Did staff clearly inform you about your relative's condition?	Yes, clearly informed	39 (60.9%)
	Yes, informed, but not clearly	17 (26.6%)
	No, not informed	8 (12.5%)
What activities do you undertake whenever you visit your relative?	Sit and talk	53 (82.8%)
	Take a walk	32 (50.0%)
	Household chores	4 (6.3%)

In Table 2 data related to visits of family caregivers are presented. The largest percentage of family caregivers visit their relative several times each week (40.6%, $n = 26$). During these visits, family members usually sit and talk or take a walk with their relative. A minority also do household chores together with their relative (6.3%, $n = 4$). Some long-term care settings invite family members to attend a meeting with professional caregivers on admission of an elderly relative with dementia. This was also the case in our sample, in which 42.2% ($n = 27$) were invited for a

meeting within six weeks following admission. In general, family members are often invited to a further meeting with the professional caregiver after the initial meeting on admission to a long-term care setting. However, the largest percentage of participants in our sample (37.5%, $n = 24$) were not invited to an additional meeting after the first meeting at the nursing home. One purpose of the meetings with staff on and after admission is to discuss the content and implementation of the care provided to the elderly relative with dementia. Meetings between family members and professional caregivers also provide an opportunity for family caregivers to obtain information about their relative's condition; 60.9% ($n = 39$) of family caregivers reported that they had generally been clearly informed about the condition of their relative.

Caregiving triangle

This study systematically tested for differences between settings, countries and measurement moments. The results for the three research questions about the 'caregiving triangle' will be described in three separate sections, in which the focus will be on the similarities and differences between traditional and small-scale long-term care settings. Mean scores for the 25 items in the questionnaire, for each type of setting, aggregated across country and measurement moment, are presented in Table 3.

Table 3. Mean scores and percentages for setting, aggregated across countries and measurement moments

Question (Range)	Traditional ($n=30$)	Small-scale ($n=34$)
<i>Family perspective on interaction between family caregiver and resident</i>		
What is the usual duration of your visits (in hours)?	1.55 (2.08)	1.93 (1.46)
What was the duration of your visits (last 14 days, in hours) cumulative?	12.24 (30.94)	11.09 (12.94)
How often did you visit your loved one in the last 14 days? (0 - 14 times)	5.28 (4.63)	5.21 (3.99)
Are you satisfied with the contact with your relative during visits (0 = never, 1 = sometimes, 2 = often, 3 = always)?	1.69 (0.84)	2.03 (0.85)
Is there anything you would like to help your relative with? (0 = no, 1 = yes)	12 (40%)	16 (47%)
Do you ever participate in activities that the nursing home is hosting? (0 = no, 1 = yes)	11 (37%)	11 (32%)
<i>Family perspective on interaction between professional caregiver and resident</i>		
Do caregivers take account of your relative's habits? (0 = no, 1 = rarely, 2 = sufficiently, 3 = a great deal)	1.96 (0.50)	1.95 (0.51)
If your relative tells caregivers something, do they react? (0 = no reaction, 1 = usually, 2 = always)	0.96 (1.00)***	1.58 (0.78)***
If your relative asks something of a caregiver, do they react? (0 = no reaction, 1 = usually, 2 = always)	1.22 (0.97)	1.55 (0.82)
Do caregivers respect your relative's world view e.g. take him/her seriously? (0 = never, 1 = rarely, 2 = usually, 3 = always)	2.38 (0.52)	2.43 (0.56)
Do caregivers appear to be in a hurry when taking care of your relative? (0 = never, 1 = sometimes, 2 = often, 3 = (almost) always)	0.73 (0.63)	0.65 (0.64)
Do caregivers ever address your relative in a derogatory fashion? (0 = no, 1 = yes)	6 (20%)	2 (7%)

Question (Range)	Traditional (n=30)	Small-scale (n=34)
Do caregivers provide support when your relative is upset? (0 = no, 1 = yes)	25 (83%)	31 (91%)
Do caregivers ever enquire about the life history of your relative? (0 = never, 1 = rarely, 2 = sometimes, 3 = often)	1.33 (0.93)	1.46 (0.92)
<i>Family perspective on interaction between family and professional caregiver</i>		
How often do you have contact with a professional caregiver on your visits? (0 = never, 1 = sometimes, 2 = often, 3 = always)	1.62 (0.76)**	2.16 (0.76)**
Are you satisfied with this contact? (0 = not at all, 1 = a little, 2 = reasonably, 3 = always)	2.05 (0.62)**	2.37 (0.60)**
Do the caregivers accept you helping your relative? (0 = no, 1 = partially, 2 = completely)	1.47 (0.64)	1.62 (0.57)
Do the caregivers make use of your advice? (0 = never, 1 = rarely, 2 = usually, 3 = always)	2.00 (0.41)	2.00 (0.47)
Is there enough room for the feelings of family members in the nursing home? (0 = never, 1 = sometimes, 2 = usually, 3 = always)	1.68 (0.89)*	2.12 (0.87)*
Do other professionals listen to you if you tell them about your relative? (0 = no, 1 = yes)	28 (93%)	32 (94%)
Are you satisfied with the contact with other professionals? (0 = no, 1 = yes)	28 (93%)	31 (90%)
Do you think your relative's care plan is appropriate for their problems? (0 = no, 1 = yes)	25 (83%)	30 (89%)
During visits, do you know which caregiver is responsible for your relative? (0 = no, 1 = yes)	16 (53%)	20 (58%)
Do you ever give advice to caregivers about how to treat your relative? (0 = no, 1 = yes)	14 (47%)	20 (58%)
Do you ever have contact with other professional caregivers (e.g. physician)? (0 = no, 1 = yes)	18 (60%)	21 (62%)

Note. Means and percentages were aggregated across country and measurement moment.

Absolute numbers indicate the mean for each setting type on the specific item with the standard deviation shown in brackets. Percentages indicate the proportion of participants for each setting answering 'yes' to the specific item.

Significantly different means and percentages (for setting) are indicated: *** $p < .001$ ** $p < .01$ * $p < .05$

The mixed models and logistic regression analyses for the three research questions yielded estimated regression coefficients, which are presented in Table 4.

Table 4. Estimated regression coefficients for setting, country and measurement moment differences

Question (Range)	Small-scale (ref) / Trad Estimated Coefficients	NL (ref) / BE Estimated Coefficients	T0 (ref) / T1 Estimated Coefficients
<i>Family perspective on interaction between family caregiver and resident</i>			
What is the usual duration of your visits (in hours)? ¹	-0.43	-0.32	0.04
What was the duration of your visits (last 14 days, in hours) cumulative? ¹	0.94	-2.95	-0.07
How often did you visit your loved one in the last 14 days? (0 - 14 times) ¹	.15	.27	-.14
Are you satisfied with the contact with your relative during visits? (0 = never, 1 = sometimes, 2 = often, 3 = always) ¹	-.35	-.10	.07
Is there anything you would like to help your relative with? (0 = no, 1 = yes) ²	-.63	.93	-.42
Do you ever participate in activities that the nursing home is hosting? (0 = no, 1 = yes) ²	-21.57	-1.57	.95
<i>Family perspective on interaction between professional caregiver and resident</i>			
Do caregivers take account of your relative's habits? (0 = no, 1 = rarely, 2 = sufficiently, 3 = a great deal) ¹	.01	-.03	.07
If your relative tells caregivers something, do they react? (0 = no reaction, 1 = usually, 2 = always) ¹	-.61**	.04	.08
If your relative asks something of a caregiver, do they react? (0 = no reaction, 1 = usually, 2 = always) ¹	-.31	.12	.12
Do caregivers respect your relative's world view e.g. take him/her seriously? (0 = never, 1 = rarely, 2 = usually, 3 = always) ¹	-.09	-.30*	.05
Do caregivers appear to be in a hurry when taking care of your relative? (0 = never, 1 = sometimes, 2 = often, 3 = (almost) always) ¹	.10	.29*	-.03
Do caregivers ever address your relative in a derogatory fashion? (0 = no, 1 = yes) ²	.00	-.97	19.47
Do caregivers provide support when your relative is upset? (0 = no, 1 = yes) ²	- a	- a	- a
Do caregivers ever enquire about the life history of your relative? (0 = never, 1 = rarely, 2 = sometimes, 3 = often) ¹	-.16	-.38	-.35*
<i>Family perspective on interaction between family and professional caregiver</i>			
How often do you have contact with a professional caregiver on your visits? (0 = never, 1 = sometimes, 2 = often, 3 = always) ¹	-.50**	-.20	.13
Are you satisfied with this contact? (0 = not at all, 1 = a little, 2 = reasonably, 3 = always) ¹	-.34**	-.17	.13
Do the caregivers accept you helping your relative? (0 = no, 1 = partially, 2 = completely) ¹	-.15	-.42*	-.22
Do the caregivers make use of your advice? (0 = never, 1 = rarely, 2 = usually, 3 = always) ¹	.01	-.21	-.12
Is there enough room for the feelings of family members in the nursing home? (0 = never, 1 = sometimes, 2 = usually, 3 = always) ¹	-.42*	.01	-.05

Question (Range)	Small-scale (ref) / Trad Estimated Coefficients	NL (ref) / BE Estimated Coefficients	T0 (ref) / T1 Estimated Coefficients
Do other professionals listen to you if you tell them about your relative? (0 = no, 1 = yes) ²	18.68	-19.24	No variance ^b
Are you satisfied with the contact with other professionals? (0 = no, 1 = yes) ²	1.31	-.69	-18.60
Do you think your relative's care plan is appropriate for their problems? (0 = no, 1 = yes) ²	-.29	.17	.38
During visits, do you know which caregiver is responsible for your relative? (0 = no, 1 = yes) ²	.14	-.29	-1.00
Do you ever give advice to caregivers about how to treat your relative? (0 = no, 1 = yes) ²	-.34	-.08	-1.13
Do you ever have contact with other professional caregivers (e.g. physician)? (0 = no, 1 = yes) ²	.45	-.88	-.43

Note. Asterisks indicate that mean scores for items differ significantly from the reference group (indicated above the columns): ** $p < .01$ * $p < .05$

¹ Items with continuous response categories were analyzed using the mixed models procedure

² Items with dichotomous response categories (no/yes) were analyzed using logistic regression

^a N was too low for analysis on this item

^b All participants in the sample gave the same response at both measurement moments, therefore no variance is present and this analysis cannot be performed

The family perspective on interaction between family caregiver and resident

Irrespective of setting, country or measurement moment, taken over the course of 2 weeks, family members visited their relatives about five to six times, for a cumulative total of about 11 hours. They were 'often' satisfied with the contact with their elderly relative with dementia. About 43% of family members liked to help their relative with a variety of activities and about 34% enjoyed participation in nursing home activities. No significant differences could be seen between the different settings, countries or measurement moments. Post hoc analyses in which we controlled for relevant background variables (sex and relationship to the resident) yielded a similar pattern of results.

The family perspective on interaction between professional caregiver and resident

Examining the relationship between the professional caregiver and the resident revealed that family members of residents in small-scale settings think that professional staff listen to the resident more than family members of residents in traditional settings ($b = -.61$, $p < .001$). There was variation between countries, in that family caregivers in the Netherlands felt that professional caregivers appeared to be in less of a hurry ($b = -.29$, $p < .05$) and to take the resident's world view more seriously, compared to family members in Belgium ($b = .30$, $p < .05$). For both types of setting and countries, family members indicated more inquiries about the life history of their relative at the baseline measurement ($b = -.35$, $p < .05$) compared to the follow-up questionnaire.

Regardless of setting, country or measurement moment, family members indicated that the habits of relatives were taken into account ‘sufficiently’ and that professional caregivers ‘usually’ listened to the things that their relatives tell or ask them and respected the world view of the resident (e.g. take him or her seriously). They almost ‘always’ tried to provide support when the resident is upset. In the view of family members, staff ‘sometimes’ appeared to be in a hurry, but not very ‘often’. Only a minority of family members had ever seen staff speaking to their relative in a derogatory fashion. Family members were ‘sometimes’ asked about the life history of their relative. No significant differences could be seen between the different settings, countries or measurement moments on these items. Post hoc analyses in which we controlled for relevant background variables (sex and relationship to the resident) yielded a similar pattern of results.

The family perspective on interaction between family caregiver and professional caregiver

Analysis of the relationship between the family and (primary) professional caregiver revealed that family members with a relative in a small-scale living facility reported that contact with the professional caregiver was more frequent ($b = -.50, p < 0.01$), and that this contact was more often satisfactory compared to family members with a relative in a traditional nursing home ($b = -.34, p < 0.01$). In addition, family members of residents in small-scale settings felt that more attention was paid to the feelings of family members as compared with traditional nursing homes ($b = -.42, p < 0.05$).

Another significant difference was found between both countries in the relationship between family and professional caregiver; according to family caregivers, help offered by family members was more often accepted by professional caregivers in settings in the Netherlands than in Belgium ($b = -.42, p < 0.05$).

Irrespective of setting, country or measurement moment, family members ‘often’ have contact with professional caregivers when they visit their relative and they are ‘reasonably’ satisfied with that contact. About 56% of family members were aware of who was responsible for their relative at a given time and thought that the care plan was appropriate for their relative. Help and advice from family members was ‘usually’ accepted and there was ‘often’ room for the feelings of family members. Contact with professionals other than the primary caregiver also ‘sometimes’ occurred and this contact was also rated positively. No significant differences could be seen between the different settings, countries or measurement moments on these items. Post hoc analyses in which we controlled for relevant background variables (sex and relationship to the resident) yielded a similar pattern of results.

Discussion

The present study was part of a larger project focusing on the quality of life of elderly people with dementia in different settings. As the number of family caregivers included in this study was dependent on the number of residents participating in the larger study (of which the required sample size was met; $n = 179$), the sample size was limited. The results should, therefore, be regarded as preliminary, and further research needs to be conducted in order to be able to draw more definitive conclusions. Despite the limited sample size, the study gives a voice to family members of residents with dementia living in two types of long-term care

facilities in Belgium and the Netherlands. It provides a closer look into the 'caregiving triangle' between family caregivers, professional caregivers and residents with dementia. The caregiving role of family members is not relinquished when their partner or parent with dementia enters the residential facility. The family caregivers in our sample visited their relative several times a week, participated in activities, but were also involved with the treatment of their relative by professional staff. In general, family members were positive about the way staff interact with and care for residents with dementia.

The expectation that family members of residents of small-scale living facilities would be more positive about the interactions between themselves, the resident and the professional caregiver was only partially confirmed. Although we did not find overall results on all items for the three research questions, the results did show a consistent pattern. As regards the effect of the type of setting for both countries, there were four interesting significant findings: in small-scale settings, contact between family members and professional caregivers was more frequent than in traditional units; this contact was also more often satisfactory, the feelings of family members were taken more into account by staff, and family members found that staff listened to the resident better. Although we found no previous research to confirm this, a possible explanation for the more frequent and more satisfactory contact between family members and staff in small-scale settings may lie in the scale of the long-term care facility. A smaller care team implies fewer changes in personnel, increasing the opportunity for family members to become more familiar with the professional caregivers. It is well known that building partnerships between residents, family members and professional caregivers starts with gaining mutual trust and understanding [27, 28]. Moreover, our results match previous findings on family and professional caregiver contact in small-scale living settings [20, 29].

However, this study also highlights another aspect, involving the relationship between the professional caregiver and the resident. The relatively better listening skills we found for professional caregivers in small-scale living settings is in line with the positive evidence about the Green House® concept in the United States, where family members in such small-scale dwellings were also more satisfied with the resident's care [20]. A possible explanation for this finding could be that the underlying care model of small-scale living facilities emphasises normalisation, with increased attention for building and maintaining qualitative relationships [9, 25].

The present study also found similarities between small-scale living facilities and larger traditional nursing homes. Frequency of visits and participation in activities by family members are the same for both types of settings in the sample; professional caregivers mostly communicate respectfully with the resident; and staff try to use the advice given to them by family members about treating the residents. These similarities fuel our impression that, rather than polarising the two kinds of long-term care settings, it would be more appropriate to see them as two specific representations of dementia care, within a broad range of different care forms, with 'scale' as only one aspect of importance.

As stated previously, the approach to dementia has moved towards a more holistic, person-centred point of view. Realising the ideal of individualised, person-centred care for persons with dementia remains a challenge, and this is represented in some of our findings. This indicates that there is room for further improvement of care practice. For example, regardless of the care setting, family members are not always invited to meetings with professional staff to discuss issues surrounding the care of the resident and their personal habits. As family members are the primary informants about the life history of the person with dementia, this offers an excellent starting point for valuing the knowledge of family members and further involving them

in the care process. This may lead to increased involvement of family members and result in higher satisfaction on the part of all three parties involved (residents, families and staff) [30].

This study also found three country differences, with family caregivers in the Netherlands perceiving staff to be in less of a hurry, finding them more open to accept help from family members, and finally judging that staff more often take residents seriously, compared to family members in Belgium. This has to be explored in future research.

There is always a chance that in some cases, participants gave socially desirable answers. However, we believe that this has been kept to a minimum in the current study, because the questions mainly concern the relationships with the professional caregiver and not with the resident. However, the strength of our study is that, although the body of literature on small-scale living units for persons with dementia is growing, this is the first time that family members' opinions about the nature and quality of interactions between themselves, residents and staff have been examined in different types of dementia care settings and in two countries. Furthermore, this is one of the few studies to have carried out a follow-up measurement after a 1-year period. However, this also implied a relatively high drop-out rate; we took the ethical decision not to approach family members of deceased participants, and drop-out was inevitable since we were dealing with family members of often very elderly and frail persons. The systematic comparison across different care settings and countries provided us with valuable insights into the partnerships between residents, family and staff. Future research could use qualitative methods to provide further in-depth insights into family caregiver perspectives.

Conclusion

An elderly person with dementia in long-term care is never an isolated entity, but has to be seen in the light of the surrounding social system. This study found some preliminary results showing that building partnerships between residents, families and staff is possibly related to satisfaction with care. We believe that this study is an example of a preliminary study showing that including the family perspective can be of value in assessing the social surroundings of elderly people with dementia. Future studies, including qualitative studies, could further evaluate the necessary components of this social system for increasing the satisfaction with as well as the quality of care for residents with dementia, both in small-scale living facilities and traditional nursing homes. Continuing efforts should be made to invest in partnerships between residents, families and staff, not just in small-scale facilities, but in all types of dementia care settings.

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Professional caregivers' mental health problems and burnout in small-scale and traditional long-term care settings for elderly people with dementia in the Netherlands and Belgium

CHAPTER 6

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Abstract

Objectives

The aim of this study was to provide an insight into burnout and mental health problems of professional caregivers working in traditional and small-scale long-term care settings for elderly residents with dementia in the Netherlands and Belgium.

Design

This study was part of a larger study investigating similarities and differences between traditional and small-scale long-term care settings for elderly residents with dementia. In this article, the perspective of the professional caregiver is of central importance. A survey was conducted among professional caregivers of residents with dementia, older than 65 years, at 2 measurement moments (at baseline and after 12 months).

Setting

The questionnaire was administered to professionals working in traditional and small-scale long-term care settings in the Netherlands and Belgium.

Participants

Professional caregivers ($n = 80$) working in 5 different care settings completed a questionnaire.

Measurements

The questionnaire included items on personal data, mental health problems (GHQ-12), and burnout (UBOS-C, divided into emotional exhaustion, depersonalization, and personal accomplishment). Analyses were conducted using Mixed Models analysis.

Results

Although mental health problems and emotional strain increased significantly over time in both types of settings and countries, overall levels of health problems and burnout were low. As regards emotional strain, professional caregivers in small-scale living facilities showed significantly increased levels in comparison with traditional units. Two significant differences between the countries were also found, with less “depersonalization” and more “personal accomplishment” in Dutch settings compared with Belgian settings. No differences emerged for type of setting or over time on “depersonalization” and “personal accomplishment.” The analyses were controlled for age, sex, educational level, and work experience in dementia care, but did not yield significant effects.

Conclusion

Owing to cutbacks in expenditure, the growing number of people with dementia, and the heavier workload, the working environment will become increasingly challenging. Future research should focus on training professional caregivers working in long-term care settings how to maximize the quality of client interaction while keeping burnout and mental health problems to a minimum.

Background

Dementia is characterized by a nonreversible, increasing deterioration of cognitive functioning [1] and is always accompanied by a need for care [2]. The number of elderly residents with dementia is increasing rapidly, and is estimated to reach no fewer than 63 million worldwide by 2030 [3], thus implying a growing demand for residential care. At the same time, institutional dementia care is transforming into a more homelike, holistic, and person-centered approach [4, 5]. A relatively new care form is the small-scale living facility, where smaller groups of elderly people with dementia reside together [6-8]. In these settings, the focus is on empowering residents to keep to their own lifestyle and continuing habits, activities of daily life, and hobbies previously performed at home for as long as possible. The differences in the organization of care and the working environment between traditional and small-scale units are apparent. For example, in small-scale units, tasks are integrated, meaning that the same staff members perform caregiving tasks, as well as housekeeping tasks, such as cooking and cleaning. A schedule can be found in Figure 1.

Figure 1. Characteristics of professional caregivers in traditional and small-scale long-term care settings

Traditional long-term care settings	Small-scale long-term care settings ^a
Number of caregivers is larger	Number of caregivers is smaller
Uniforms are worn by staff	No uniforms are worn by staff
Large amount of task differentiation	Tasks are integrated
More collective decision-making by staff	More individual decision-making by staff
Routine day schedule	Day schedule according to residents' preferences
Main focus on basic technical caregiving skills	Additional focus on client interaction

^a Small-scale living settings in Belgium are usually larger (8-15 residents), compared to these settings in the Netherlands (6-8).

These differences between small-scale living facilities and traditional long-term care settings could have implications for the pressure of work experienced by professional caregivers. In general, nursing is considered to be a challenging job and can be experienced as stressful [9]. Moreover, higher levels of stress [10], as well as increased impairment in the patient's ability to communicate [11], influence the risk of burnout and mental health problems. Although the stress of relatives caring for an elderly family member with dementia has been investigated to a large extent, stress in professional caregivers has been studied less often [11]. The few European studies on small-scale living show that working in small-scale living settings provides more feelings of competence [12], higher job satisfaction [12-14], and lower burnout rates [13, 14]. One other study found no overall effects for burnout, but found fewer burnout symptoms in small-scale living settings, analyzing a subset of the most typical small-scale and traditional settings in its sample [15]. Owing to the limited amount of research on this topic and the relatively strong focus on job satisfaction in these studies, the present study was designed to examine differences in work-related mental health problems and burnout in small-scale and traditional long-term care settings. An additional aim was to compare results and examine contextual differences across the Netherlands and Belgium. The use of data from two different countries affords the possibility of comparison and provides an opportunity to learn from each other.

The Netherlands and Belgium have comparable forms of small-scale living facilities, are geographically adjacent, and share the same native language (Dutch), enabling the use of the same measurement instruments. Although the countries differ in the number of residents per unit, with larger groups of residents and fewer hours of care per resident available in Belgian settings, the vision on small-scale living that is used is the same. The research question addressed in this study is: “Are there differences in work-related mental health problems and burnout for professional caregivers working in traditional versus small-scale long-term care settings for elderly people with dementia in the Netherlands and Belgium?” Based on the small amount of previous research [12–15], professional caregivers in small-scale living facilities are expected to show fewer symptoms of burnout and fewer mental health problems than their counterparts in traditional facilities.

Methods

Design

The study was part of a larger quasi-experimental longitudinal study on the similarities and differences between traditional and small-scale long-term dementia care settings, examining residents, family, and professional caregivers in the Netherlands and Belgium [16]. A survey was administered among professional caregivers at two measurement moments (at baseline and after 12 months). This longitudinal design was used to avoid the possibility of acquiring only a random indication at a given moment in time. The ethics committee at the De Wever care organization in Tilburg, the Netherlands, gave its approval for the complete trial in September 2008.

Participants

The same five long-term care settings in the Netherlands and Belgium that took part in the larger study comparing small-scale and traditional care settings [16] also participated in the current study. Professional caregivers working in direct care on permanent employment contracts were invited to participate. These caregivers provide care to cognitively and sometimes physically impaired elderly people older than 65 years with dementia, residing in (closed) care units.

Procedure

Professional caregivers ($n = 185$) in small-scale ($n = 41$ for the Netherlands, $n = 48$ for Belgium) and traditional care settings ($n = 54$ for the Netherlands, $n = 42$ for Belgium), received a questionnaire at their home address at baseline, including a letter explaining the project and a return envelope. Participation was voluntary and data were handled anonymously. The first questionnaire was completed by 141 of the 185 professional caregivers (response: 76.22%). Twelve months later, 50 professional caregivers who had received the baseline questionnaire had either been internally transferred to another unit, had retired, or had changed jobs. The 135 remaining professional caregivers in the units were invited to take part in the follow-up measurement, to which 90 caregivers responded (response: 69.67%). The 80 professional caregivers who had completed both questionnaires were included in the analyses. Possible reasons for nonresponse to one or both mailings (baseline and/or after 12 months) included (severe) illness or no interest in participating.

Measurements

The survey contained questions about basic personal characteristics, work-related mental

health problems, and burnout. In addition, data were collected on the characteristics of the participating care settings.

Work-related mental health problems were measured using the General Health Questionnaire (GHQ-12) (Cronbach's $\alpha = 0.76$). This is a 12-item measure of current mental health status, derived from a larger 60-item instrument. Research has shown that the shorter version provides comparable results to the longer version and is fit for use in busy clinical settings [17]. It has a 4-point response scale (corresponding to symptom presence: 0 = not at all, 1 = same as usual, 2 = rather more than usual, or 3 = much more than usual) [17].

Burnout was conceptualized as a psychological state of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur in individuals who have an occupation involving frequent client interaction. A Dutch translation of the Maslach Burnout Inventory (MBI), renamed the Utrechtse Burnout Schaal (UBOS) [18], was used to measure burnout. In this study, the UBOS-C was used (Cronbach's $\alpha = 0.79$), which was specifically developed for occupations with frequent client interaction. The results can be used for both individual diagnostic assessment and for comparisons of groups. The UBOS-C consists of 20 items that can be answered on a 7-point scale, ranging from 0 (never) to 6 (every day). Three subscale scores are available: emotional exhaustion (8 items; a higher score means more exhaustion), depersonalization (5 items; a higher score means more depersonalization), and personal accomplishment (7 items; a higher score means more personal accomplishment).

Statistical Analysis

Four analyses were performed, using the mixed models procedure in SPSS Inc. (2009), allowing for inclusion of repeated measurements of the same subjects. The first analysis examined differences between settings, countries, and measurement moments on GHQ-12 scale scores (work-related mental health problems); whereas the other three analyses examined the differences on the UBOS-C subscales (emotional exhaustion, depersonalization, and personal accomplishment). In all 4 analyses, the variables of type of setting, country, and measurement moment were included in the model simultaneously. As a result, the estimated coefficients represent the unique effects on the dependent variable, keeping the other factors stable. Subsequently, relevant background variables (age, sex, educational level, and work experience in dementia care) were also included in the analyses, to check for possible moderating effects. Last, correlation analyses were conducted.

Results

Characteristics of Participants and Care Settings

The basic characteristics of the professional caregivers presented by country and type of setting can be found in Table 1. Participants ranged in age from 21 to 59 years, and women were over-represented (92.5%). The complete range of educational levels (low, medium, and high) was present in all settings, and work experience in dementia care ranged from "less than 6 months" to "over 10 years."

Data on characteristics of care settings presented by country and type of setting are presented in Table 1.

Table 1. Basic characteristics of professional caregivers and care settings

Basic characteristics of professional caregivers (n=80)				
	Netherlands traditional (2 wards, n=23)	Netherlands small-scale ^a (8 wards, n=25)	Belgium traditional (2 wards, n=14)	Belgium small-scale ^a (4 wards, n=18)
Age, M (SD)	44.26 (12.69)	42.48 (10.96)	41.64 (10.05)	39.78 (10.04)
Women, n (%)	20 (87.0%)	24 (96.0%)	13 (92.9%)	17 (94.4%)
Education, n (%) ^b				
<i>No or little education</i>	13 (56.5%)	5 (20.0%)	3 (21.4%)	2 (11.1%)
<i>Low to medium</i>	8 (34.8%)	19 (76.0%)	6 (42.9%)	8 (44.4%)
<i>Higher education</i>	2 (8.7%)	1 (4.0%)	5 (35.7%)	8 (44.4%)
Work experience, n (%)				
< 1 year	2 (8.7%)	1 (4.0%)	3 (21.4%)	1 (5.6%)
1 - 5 years	7 (30.4%)	5 (20.0%)	2 (14.3%)	3 (16.7%)
5 years <	14 (60.9%)	19 (76.0%)	9 (64.3%)	14 (77.8%)
Descriptive characteristics of care settings				
Staff formation FTE ^c				
<i>Management</i>	0.95	0.72	1.00	0.90
<i>Nurses</i>	0.50	0.00	3.65	1.28
<i>Nurse assistants</i>	18.00	11.23	8.04	10.97
Cumulative FTE ^c	19.45	11.95	12.67	13.15
Number of residents per unit, n	30 (2 living rooms with 15 residents)	12 (2 living rooms with 6 residents)	30 (2 living rooms with 15 residents)	30 (2 living rooms with 15 residents)
Available hours of care per capita, in hours per week ^c	23.34	35.85	16.05	16.66
Sick leave % ^d	5.23	5.01	10.16	3.48

^a Small-scale living settings in Belgium are usually larger (8-15 residents), compared with these settings in the Netherlands (6-8).

^b The Dutch traditional wards differ significantly from the Belgian traditional wards ($p < .01$); The Dutch small-scale wards differ significantly from the Belgian traditional wards ($p < .05$).

^c FTE's are calculated on the basis of data provided by the nursing homes. A single FTE consists of 36 working hours in the Netherlands and 38 working hours in Belgium. Only nurses and nursing assistants were included (e.g. no medical doctors, physiotherapists, psychologists etc.).

^d Percentages are based on cumulative FTE and represent sick leave, excluding pregnancy absence in the period under study.

It can be seen that the number of residents in small-scale care units was larger and fewer hours of care were available per resident in Belgium compared with the Netherlands.

Work-Related Mental Health Problems

The mean scores on the GHQ-12 are presented by country, type of setting, and measurement moment in Table 2. Overall scores on the GHQ-12 range from 8.93 to 15.24 on a scale from 0 to 36, indicating moderate levels of mental health problems.

Work-related mental health problems showed no significant differences between type of setting or country. Although the overall level of mental health problems was low to moderate, it

did increase over time in all groups ($P < .001$). No significant moderating effects were found for basic personal characteristics.

Burnout

The mean scores on the subscales of the UBOS-C are also presented by country, type of setting, and measurement moment in Table 2.

Table 2. Mean scores at baseline and after 12 months for professional caregivers in Belgian and Dutch small-scale and traditional settings ($n=80$)

Question	Measurement	Belgium ($n = 32$) ^{a,b}		The Netherlands ($n = 48$) ^{a,b}	
		Traditional ^c ($n=14$)	Small-scale ^c ($n = 18$)	Traditional ^c ($n = 23$)	Small-scale ^c ($n = 25$)
GHQ-12 ^d	Baseline	8.93 (3.12)	10.76 (3.75)	9.76 (3.91)	8.96 (3.21)
M (SD)	12 months ^e	12.07 (5.94)	12.94 (5.03)	9.77 (4.26)	15.24 (7.59)
UBOS-C ^d	Baseline	1.33 (1.31)	1.63 (1.08)	1.04 (0.85)	1.68 (1.09)
Emotional Exhaustion M (SD)	12 months ^f	1.51 (1.29)	2.10 (1.27)	1.36 (1.13)	1.82 (1.41)
UBOS-C ^d	Baseline	0.56 (1.00)	0.89 (0.62)	0.47 (0.50)	0.56 (0.54)
Depersonalization M (SD)	12 months	0.83 (0.99)	0.93 (0.56)	0.56 (0.65)	0.54 (0.47)
UBOS-C ^d Personal Accomplishment M (SD)	Baseline	4.65 (0.57)	4.34 (1.03)	4.76 (0.66)	5.03 (0.63)
	12 months	4.55 (0.77)	4.39 (0.81)	4.73 (0.73)	4.92 (0.66)

GHQ-12, General Health Questionnaire, 12-item measure of current mental health status; UBOS-C, Utrechtse Burnout Schaal specifically developed for occupations with frequent client interaction.

^a More depersonalization is seen in Belgium, compared to the Netherlands ($p < .05$).

^b Less personal accomplishment is seen in Belgium, compared to the Netherlands ($p < .01$).

^c Emotional exhaustion was slightly higher in small-scale settings, than in traditional settings ($p < .05$).

^d For the GHQ-12 higher scores indicate more health problems (range 0-36). Higher scores indicate more emotional exhaustion and depersonalization, but better rated personal accomplishment (all range 0-6).

^e Overall, health problems and increased over time in all groups ($p < .001$).

^f Overall, emotional exhaustion increased over time in all groups ($p < .05$).

Overall scores on the emotional exhaustion scale of the UBOS-C ranged from 1.04 to 2.10 on a scale from 0 to 6, indicating low levels of emotional strain. However, Mixed Models analysis on the effects of type of setting, country, and measurement moment on emotional exhaustion showed significantly more emotional strain in small-scale than in traditional settings ($P < .05$) and an overall increase over time was seen in both types of settings ($P < .05$).

Depersonalization scores on the UBOS-C ranged from 0.54 to 0.93 on a scale from 0 to 6, indicating low levels of depersonalization. Personal accomplishment scores ranged from 4.34 to 5.03 on a scale from 0 to 6, indicating moderate to high levels of personal accomplishment. In Mixed Models analyses on the effects of type of setting, country, and measurement moment on the 2 subscales, no significant differences emerged for type of setting or measurement moment. Differences were found for country, indicating significantly more depersonalization in Belgium ($P < .05$), whereas personal accomplishment is rated lower in Belgium ($P < .01$) compared with the Netherlands. No significant moderating effects were found for basic personal characteristics.

Burnout and Mental Health Problems

In addition, correlation analyses were conducted on all participants in the study ($n = 80$). Emotional exhaustion shows a significant positive correlation ($r = 0.58$, $P < .01$) with depersonalization, and a significant positive correlation ($r = 0.70$, $P < .01$) with mental health problems. Depersonalization also shows a significant positive correlation with mental health problems ($r = 0.46$, $P < .01$). Other correlations do not reach appropriate significance levels.

Discussion

Although the aim of the study was to examine differences in mental health problems and burnout between professional caregivers of residents with dementia in small-scale and traditional long-term care settings in two countries, not many were found; however, the main finding of the study was that, regardless of type of setting or country, there was a significant increase in emotional strain and mental health problems over time. A possible explanation for this might be that in both countries investigated, major and ongoing cutbacks in expenditures on care have been introduced by the governments in recent years [8]. This implies that the same work has to be carried out with fewer professionals and that less money is available for units to fund their work. Moreover, greater demands are being placed on organizations to prove that they are providing adequate and tailor-made quality of care for their residents, leading to increased bureaucracy. Last, another possible explanation is that people who are institutionalized in long-term care settings form a group who are relatively more severely impaired, because they stay at home longer than was previously the case [19]. Despite the increase in emotional strain and mental health problems, levels of health problems and burnout experienced by professional caregivers in all long-term care settings were low to moderate.

We also found an interesting difference between small-scale and traditional settings in both countries that could not be explained by control variables. In line with other studies, overall levels of emotional strain were low [12-15]. Contrary to these studies [12-15] however, participants in our study showed significantly more emotional exhaustion in small-scale living settings compared with traditional settings. Support from colleagues is an essential ingredient for professional caregivers working in small-scale living facilities to function successfully [20]. When working alone and carrying out a wide range of different tasks, however, as is often the case in small-scale living settings, professional caregivers might experience diminished support. This aspect of working in small-scale settings is therefore something that deserves extra attention. Moreover, in the small-scale units, next to caregiving tasks, the nursing staff also takes care of cooking and cleaning, for which there are no additional staff members. This might limit the amount of time the staff has for purely caregiving activities, which might be one of the causes for the increased emotional exhaustion. In addition to differences between types of settings and over time, this study also compared professional caregivers in the Netherlands and Belgium. In both types of settings, the professional caregivers in the Netherlands recorded lower depersonalization and higher personal accomplishment scores compared with Belgium. These differences can probably be accounted for by the larger number of residents who have to be cared for by a single caregiver and the smaller number of hours available for care per resident in Belgium (Table 1). Unfortunately, this hypothesis could not be tested in the present study.

In addition, overall correlation analyses revealed that professional caregivers who are more emotionally exhausted, experience more depersonalization and mental health problems.

The most plausible explanation is that professionals who experience more emotional exhaustion, search for less personal attachment. Moreover, professional caregivers who experience more depersonalization, show more mental health problems as well. Both emotional exhaustion and depersonalization are thus linked to mental health problems. It is possible that the mental health problems (such as worrying more and having lower self-esteem) are connected with the feelings of emotional exhaustion and depersonalization at work.

One limitation of this study was the absence of a measurement of job satisfaction; however, taking into account the workload placed on the professional caregivers by participation in this and the larger study, the questionnaire had to be kept concise. Another limitation was the relatively high dropout rate. This dropout rate included a combination of internal transfers, retirement, and job changes; phenomena that fit in with real-life care settings. The latter also meant that randomization was impossible for this study.

Conclusion

Cutbacks in expenditure, more bureaucracy owing to increased accountability, the growing number of people with dementia, and the heavier workload caused by the fact that admission to a long-term care setting is delayed longer than in the past, mean that the working environment in care home settings will become increasingly challenging. This can be seen in our study in the increase in emotional strain and mental health problems over the course of the year in all settings. It is therefore important that professional caregivers in both types of settings possess adequate knowledge and skills to be able to function optimally in their working environment. Future research should investigate what basic and specialized skills are needed and how they might be implemented in regular nursing training. Moreover, to make the working environment as healthy as possible, it might be beneficial to be able to match specific work settings to professional caregivers with the right skills. Training professional caregivers working in long-term care settings might help maximize the quality of client interaction while keeping burnout and mental health problems to a minimum.

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General discussion

CHAPTER 7

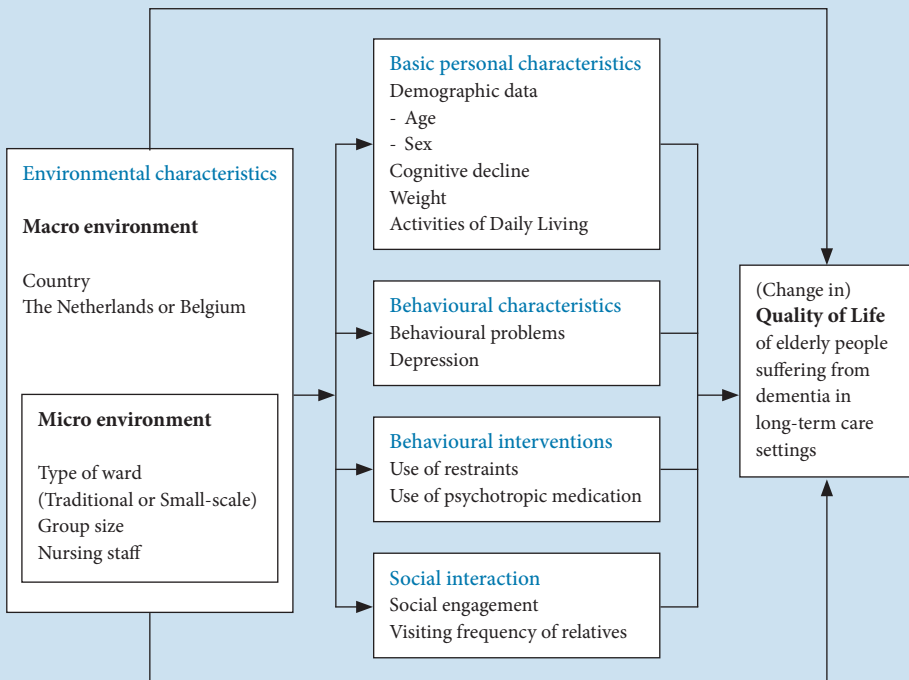
Introduction

Good quality of care for persons with dementia involves, adequate medical, nursing and paramedic care, psychosocial coaching and meaningful timesharing, but also supporting family caregivers and attention for a home-like, qualitative high standard of living [1]. Due to the aging society, the number of people with dementia is increasing rapidly worldwide [2], placing greater demands on organizations to provide innovative care solutions. The increased demand for residential care can be handled by creating additional places within existing traditional care centres, but also by creating places in new care facilities, for example small-scale living facilities [3]. These facilities are designed to offer home-like, holistic and person-centred care for older people with dementia. Because so many people suffering from dementia are in need of residential care, it is of utter importance, to investigate the effects of different forms of residential care in a reliable and valid way.

This thesis provides insight into the differences and similarities between small-scale and traditional long-term care settings in the Netherlands and Belgium, from the perspectives of residents with dementia, their family, and professional caregivers working in these settings. Collecting data on various aspects, in different countries and settings is of added value, because of the learning opportunities and because it may enable to discern more clearly certain patterns in the data.

This chapter summarizes and discusses the main findings and relates them to existing literature. It also discusses research limitations and provides recommendations for future research as well as for dementia care practice.

Figure 1. Conceptual model of the resident related study part



Main findings

Residents

To determine differences and similarities in quality of life, functional status, behaviour and social interaction between residents with dementia living in small-scale and traditional long-term care settings, professional caregivers filled in validated questionnaires based on observations for 179 residents. For this part of the study, a conceptual model was designed (Figure 1). The results of this part of the study were acquired by using multilevel analyses.

Three-level models were employed and each quality of life subscale was analysed separately. Although the small-scale and traditional settings were respectively selected on the basis of comparable characteristics, in these statistical analyses the patterns appeared to differ too much to justify aggregation over countries. When the results would have been aggregated over countries, it would have been unclear to what possibly found differences could be ascribed to. After conducting the multilevel analyses within the countries, it was, however, possible to

Table 1. Schematic overview of within-country *comparisons of means* (aggregated across time)

	The Netherlands		Belgium	
	Traditional	Small-scale	Traditional	Small-scale
Quality of Life				
Caregiver relation	0	0	0	0
Positive affect	-	+	0	0
Negative affect	0	0	-	+
Positive self-image	0	0	0	0
Social relations	-	+	0	0
Social isolation	0	0	0	0
Feeling at home	0	0	0	0
Restless behaviour	0	0	0	0
Having something to do	-	+	0	0
Other patient outcomes				
Activities of Daily Living (ADL)	-	+	-	+
Behavioural problems*	0	0	0	0
Depression*	0	0	+	-
Use of restraints*	0	0	0	0
Prescription of psychotropic medication*	0	0	0	0
Social engagement	-	+	0	0
Visiting frequency of relatives	0	0	0	0

Note. The first set of aspects represents quality of life domains (chapter 3), the second set represents patient outcomes (chapter 4). Higher scores on quality of life domains always mean a better quality of life on this aspect. This is also the case for ADL, social engagement and visiting frequency. Aspects indicated with an asterisk (*) are aspects are negatively formulated, implying that higher scores on these aspects mean more behavioural problems, more depression, more restraints and more psychotropic medication.

In this table, + means a significantly higher score on this aspect in this setting, - means a significantly lower score on this aspect in this setting, 0 means no significant differences on this aspect in this setting.

compare the found patterns.

A first set of analyses (chapter 3) estimated means for the different quality of life subscales and compared these means across the traditional and small-scale settings within the Netherlands and Belgium. A second set of analyses (chapter 4) estimated means for other patient outcomes: functional status, behaviour and social interaction, and compared these means using the same technique. Table 1 shows a schematic overview for each of the countries of the significant differences and the similarities in means between residents living in traditional and small-scale living facilities, separately for quality of life domains (chapter 3) and other patient outcomes (chapter 4).

Comparisons of means (Table 1)

In the Netherlands residents in small-scale settings showed a better quality of life on the domains 'Positive affect', 'Social relations' and 'Having something to do'. The finding on 'Having something to do' is in line with other studies [4, 5]. Residents in small-scale settings in the Netherlands also showed better ADL scores, and more social engagement, compared to their counterparts in traditional settings.

In Belgium, residents in small-scale settings had better quality of life on the domain 'Negative affect' (they had less negative affect) and both better scores on ADL and lower depression scores, compared to traditional settings. The finding on 'Negative affect' is contrary to previous research, where lower quality of life was found on this aspect for small-scale living facilities [5].

To look at changes over time, a third set of analyses examined the different quality of life subscales for traditional and small-scale settings in the Netherlands and Belgium. To look at changes over time for other patient outcomes, in addition, a fourth set of analyses was conducted in the same manner. Table 2 shows a schematic overview for each of the countries of the significant differences and the similarities in changes over time between residents living in traditional and small-scale living facilities, separately for quality of life domains (chapter 3) and other patient outcomes (chapter 4). The presented results are new, because to our knowledge, there are no other studies examining these specific domains of quality of life and patient outcomes, across time.

Effects over time (Table 2)

In the Netherlands, residents in small-scale settings showed a decrease in quality of life over the course of one year on the aspects 'Positive affect' and 'Social relations', as well as a decrease in social engagement, whereas traditional settings remained stable on these aspects. Moreover, an increase was seen in the prescription of psychotropic medication. Residents in traditional settings in the Netherlands showed a decrease in quality of life over the course of one year on the aspects 'Caregiver relation' and 'Negative affect'. However, contrary to our expectations, residents in traditional settings showed a decrease in behavioural problems. ADL scores decreased for both types of settings.

In Belgium, residents in small-scale settings showed a decrease in quality of life over the course of one year in 'Social relations', 'Restless behaviour' and 'Having something to do', as well as a decrease in social engagement. Moreover, they showed an increase in the degree of depression, and in use of restraints and prescription of psychotropic medication. ADL scores of residents decreased for both types of settings. We also found that the visiting frequency of relatives increased small-scale settings in Belgium. Like in the Netherlands and contrary to our expectations, we found that residents in traditional settings in Belgium also decreased in behavioural problems. Moreover, but only for residents in Belgian traditional settings, we found that the quality of life increased over the course of the year on the aspect 'Feeling at home'.

Table 2. Schematic overview of *effects over time* within-country

	The Netherlands		Belgium	
	Traditional	Small-scale	Traditional	Small-scale
Quality of Life				
Caregiver relation	-	0	0	0
Positive affect	0	-	0	0
Negative affect	-	0	0	0
Positive self-image	0	0	0	0
Social relations	0	-	0	-
Social isolation	0	0	0	0
Feeling at home	0	0	+	0
Restless behaviour	0	0	0	-
Having something to do	0	0	0	-
Other patient outcomes				
Activities of Daily Living (ADL)	-	-	-	-
Behavioural problems*	-	0	-	0
Depression*	0	0	0	+
Use of restraints*	0	0	0	+
Prescription of psychotropic medication*	0	+	0	+
Social engagement	0	-	0	-
Visiting frequency of relatives	0	0	0	+

Note. The first set of aspects represents quality of life domains (chapter 3), the second set represents patient outcomes (chapter 4). Higher scores on quality of life domains always mean a better quality of life on this aspect. This is also the case for ADL, social engagement and visiting frequency. Aspects indicated with an asterisk (*) are aspects are negatively formulated, implying that higher scores on these aspects mean more behavioural problems, more depression, more restraints and more psychotropic medication.

In this table, + means a significant increase on this aspect in this setting, - means a significant decrease on this aspect in this setting, 0 means stability on this aspect in this setting.

Family

An older person with dementia in long-term care is never an isolated individual, but has to be considered in the light of the surrounding social system, of which family members are an important part, also after moving to a residential setting. Our study provides a closer look into the 'caregiving triangle' between family caregivers, professional caregivers and residents with dementia. For this part of the study family members of residents who participated in the resident study were invited to fill in a questionnaire twice, with a time interval of one year. Only 64 family members completed the questionnaire both at baseline and after one year. Mixed Models analyses were conducted, simultaneously examining the effects of type of setting, country, and changes over time on family perspectives. The family caregivers in our sample visited their relative several times a week, participated in activities, but were also involved in the care for their relative by professional staff. In general in both types of settings and countries, family members were positive about the way staff interact with and care for residents with dementia.

The expectation that family members of residents of small-scale living facilities would be more positive about the interactions between themselves, the resident and the professional caregivers was only partially confirmed.

Regarding the effect of the type of setting, for both the Netherlands and Belgium, there were four interesting findings: in small-scale settings, contact between family members and professional caregivers was more frequent than in traditional units; this contact was also more often satisfactory; the feelings of family members were taken more into account by staff, and family members stated that staff listened better to the residents. Our results match with previous findings on family and professional caregiver contact in small-scale living settings [5, 6]. A possible explanation for the more frequent and more satisfactory contacts between family members and staff in small-scale settings may be found in the smaller size and the continuity in the composition of the care team, where the same professionals often provide care for the resident, which subsequently increases the opportunity for family members to become more familiar with these professional caregivers.

This study also highlighted another aspect, involving the relationship between the professional caregiver and the resident. We found relatively better listening skills for professional caregivers in small-scale living settings as perceived by family. A possible explanation for this finding could be that the underlying care model of small-scale living facilities emphasises normalization, with increased attention for building and maintaining qualitative relationships [1, 7].

The study on family perspectives also found similarities between small-scale living and traditional facilities. Frequency of visits and participation in activities by family members were the same for both types of settings in the sample; professional caregivers mostly communicate respectfully with the residents; and staff tries to use the advice given to them by family members about treating the residents. These similarities fuel our impression that, rather than polarizing the two kinds of long-term care settings, it would be more appropriate to see them as two specific representations of dementia care, within a broad range of different care forms, with 'scale' as only one aspect of importance.

The study on family also showed three differences between Belgium and the Netherlands, regardless of the type of setting. Compared to family members in Belgium, family members in the Netherlands perceived staff to be in less of a hurry, finding them more open to accept support from family members and judging that staff more often take residents seriously.

Professional caregivers

For the study discussed in chapter 6, data were gathered on mental health problems and burnout of professional caregivers of residents with dementia in small-scale and traditional long-term care settings. Professional caregivers (N=80) filled in the questionnaire both at baseline and after one year. These data were analysed with a Mixed Models procedure, simultaneously examining the effects of type of setting, country, and changes over time on mental health problems and burnout. First, overall correlation analyses revealed that professional caregivers who are more emotionally exhausted, experience more depersonalisation and mental health problems. Moreover, professional caregivers that experience more depersonalisation, show more mental health problems as well. Both emotional exhaustion and depersonalisation are thus linked to mental health problems.

Although levels of health problems and burnout experienced by professional caregivers in all long-term care settings were low to moderate, there was a significant increase in emotional strain and mental health problems over time in both small-scale and traditional setting

in the Netherlands as well as in Belgium. A possible explanation for this might be that in both countries, in recent years the severity of dementia of admitted residents has increased, resulting in a heavier workload for the professional caregivers. Nowadays, residents with dementia who are institutionalized in long-term care settings represent a group that is relatively more severely impaired, because they stay at home longer than was previously the case [8].

In addition, the workload of professional caregivers has also increased by more bureaucracy and mandatory recording of a huge number of data on how care is provided for each individual resident. Moreover, organizations have become more visible for the public and they get more media attention. In this way, greater demands are being put on organizations and professional caregivers to prove that they are providing adequate and tailor-made care of high quality for their residents.

We also found an interesting difference between small-scale and traditional settings in both countries, in that participants in our study showed significantly more emotional exhaustion in small-scale living settings. This is contrary to previous findings [5, 9-11]. However, in line with these studies, overall levels of emotional strain remained low [5, 9-11]. Support from colleagues is an essential ingredient in the work of professional caregivers in all types of settings [1]. However, in a small-scale living facility, when working alone and carrying out a wide range of different tasks, professional caregivers might experience diminished support. This aspect of working in small-scale settings is therefore something that deserves extra attention. Moreover, in small-scale units, next to caregiving tasks, the nursing staff also takes care of household tasks. This might limit the amount of time the staff has for purely caregiving activities, which could be also one of the causes of the observed increased emotional exhaustion.

Furthermore, there are some differences between professional caregivers in the Netherlands and Belgium, regardless of type of setting. The professional caregivers in the Netherlands recorded lower 'depersonalization' and higher 'personal accomplishment' scores compared to Belgium. These differences can probably be accounted for by the larger number of residents who have to be cared for by a single caregiver and the smaller number of hours available for care per resident in Belgium.

Limitations of the studies

The next part of this discussion considers some relevant methodological and theoretical issues that may have influenced and restricted the results of our studies.

First, the settings in this study represent real-life care settings of which specific characteristics may differ and influence the results of our study. Therefore, it could be that settings in both countries differed on some aspects that were not taken into account, such as length of existence, design of the environment, culture, atmosphere and composition of the team of professional caregivers. Moreover, there are differences between both countries in funding and legislation of health care as well as in the organization and implementation of residential care.

Second, conducting a study like this one as a randomised controlled trial, is viewed as being the best design. However, in the overall study described in this thesis this was not possible due to practical and ethical considerations. Residents lived in the real-life care settings that were included in this study and it would be impossible to make them move only for the purpose of the study.

A new aspect of the studies presented in this thesis, compared to other studies, is that patterns in differences and similarities of outcomes could be compared in two different countries, namely the Netherlands and Belgium.

In the resident part of the study, we were mainly interested in changes over time. Therefore, multilevel analysis was conducted, being a good strategy of analysis to examine longitudinal research data. However, the patterns between Belgium and the Netherlands appeared to differ too much to justify aggregation over countries in these analyses.

In the family and professional caregiver studies, two measurement moments were used to prevent giving only a random indication at a certain point in time. Because we did not expect differences over time, for these studies Mixed Models analyses were conducted, making country comparisons possible.

Residents

At baseline, the resident groups, although comparable, were not completely equivalent. Therefore, we controlled the analyses for differences in functional status, cognitive impairment and basic personal characteristics. However, a limitation of our study is that we did not account for differences in the duration of exposure to the type of setting, as well as for differences in the history of caregiving of the individual residents.

Furthermore, in the resident study we aimed to assess quality of life as a multidimensional concept. Therefore, we used the Qualidem scale as it is supposed to be used, by separately discussing scores on the nine different domains of quality of life [12]. Because this method is meant to capture the subtlety of the concept, we decided not to calculate a total score of quality of life. Although this conceptualization and assessment strategy provided more detailed and in-depth data, like other researchers [4, 5], we were unable to establish consistent findings. The question remains whether it is possible to measure quality of life of older people with severe dementia in a quantitative way at all and whether it is possible to measure a subjective concept in an objective way in the first place.

This brings us to discuss another limitation, because due to the progressive cognitive deterioration, self-report by older residents with dementia was impossible. Data had to be gathered through proxy reports from professional caregivers. The disadvantage of proxy ratings is that they filter a subjective measure through the opinion of another person. Nevertheless, observation by one or more professional caregivers is considered to be the best, most reliable and valid alternative method in the target group we have studied [13].

Because of these issues it might be recommended to search for other methods to determine quality of life of people with severe dementia. For example, future research could employ more qualitative and mixed methods, with other types of observation strategies (e.g. Dementia Care Mapping [14]) which might provide more in-depth insight and a better understanding of the patterns that were found in our studies on the residents.

Family

As the number of family members included in this study was dependent on the number of residents participating in the resident study (N=179), the sample size was limited (N=64). The results of our study should therefore be regarded as preliminary and further research needs to be conducted in order to be able to draw more definite conclusions.

Furthermore, there is always a chance that in some cases participants gave socially desirable answers. However, we believe that this has been kept to a minimum in the current study, because questionnaires were filled in completely anonymous and were directly

sent to the researchers, without involvement of the participating organizations.

The strength of our study is that, although the body of literature on small-scale living facilities for persons with dementia is growing, this is one of the first in which family members' opinions about the nature and quality of interactions between themselves, residents and staff have been examined in different types of dementia care settings (small-scale and traditional) and in two countries (The Netherlands and Belgium). Moreover, this is one of the few studies that has carried out a follow-up measurement after a one-year period, avoiding presenting only a random indication at a given moment in time. However, this also implied a relatively high drop-out rate, due to the increased mortality rate of the frail and very old resident group. We made the ethical decision not to approach family members of deceased residents.

To support the findings of our study on family perspectives and to gain more insight into the social relations within the 'caregiving triangle', future studies should try to incorporate larger participant groups, to be able to draw more definite conclusions.

Professional caregivers

The method of inclusion of professional caregivers into the study, might have introduced selection bias, because individuals are free to choose the type of work environment they think is best suitable for their skills and may differ on personal characteristics. However, we did control for some basic personal characteristics, such as age, sex, education and experience in dementia care.

Furthermore, the turnover rate among professional caregivers in the care sector is relatively high [15]. In this study, this also was the case and turnover was due to a combination of internal transfers, retirement and job changes; phenomena that match with real-life care settings.

Our study shows that it is not only important to provide a good care environment for older people with dementia and their families, but also to keep in mind that the settings should provide a healthy workplace for professional caregivers as well. Therefore, future research should investigate in more detail the place of the professional caregiver in the context of the specific care environment and the dynamics within the total 'caregiving triangle'.

Implications for dementia care practice and policy

In the Netherlands, the vision that small-scale care settings are more beneficial for residents with dementia still dominates current institutional dementia care policy. However, in Belgium, there are less initiatives of small-scale living. This is not due to a lower confidence in the vision, but to consideration about the financial feasibility in view of the way in which nursing home care is funded in Belgium. However, the findings from this thesis and other studies do not provide unconditional support for the assumption that living in small-scale settings is more beneficial for all residents with dementia.

The basic assumption of dementia care practice should be providing good quality of care for residents with dementia and their family, while keeping the work environment for professional caregivers as healthy as possible. Up until now, small-scale living has been considered the best suitable environment to do so. However, the lack of convincing evidence of our studies and that of others, suggest that small-scale living facilities do not necessarily and exclusively provide the best conditions to achieve this goal. We have found that for some aspects small-

scale living facilities might have an advantage, but for other aspects we have seen traditional care settings score better. This means that we have to extract the best aspects from both types of living settings and place the people in the 'caregiving triangle' at the center of attention, rather than focusing primarily on the scale of residential long-term dementia care settings.

The findings presented in this thesis have implications for daily care policy and practice. Developing and investing in differentiated types of residential care facilities instead of focusing mainly on small scale facilities for people with dementia and taking into account the residents' own individual wishes and preferences as well as those of their family members, currently seems the best strategy. Seeking for the right match between the life history of an individual resident and the type of care setting could prove to be beneficial for quality of life in general. It is a challenge to develop an assessment method to target the type of long-term care setting that best matches the resident with dementia.

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Appendix Summary

Samenvatting (Summary in Dutch)

Dankwoord (Acknowledgements)

Curriculum vitae

List of publications

Appendix

The Qualidem measure has been included in the Appendix to clarify the method of measuring quality of life in older persons with dementia in Chapter 3.

Ettema, T. P., Dröes, R.M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W., QUALIDEM: Development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *International Journal of Geriatric Psychiatry*, 2006. 22: p. 549-556.

Ettema, T. P., Dröes, R.M., Lange de, J., Mellenbergh, G. J., & Ribbe, M. W., QUALIDEM: Development and evaluation of a Dementia Specific Quality of Life Instrument - validation. *International Journal of Geriatric Psychiatry*, 2007. 22: p. 424-430.

Qualidem

Name of resident:

Ward:

The questionnaire contains 40 questions. The objective is that you, together with a colleague, answer the questions about the past week, in which you have observed the resident. Please answer every question. If you hesitate between two possibilities, circle the figure below the answer that is most in line with your observations. An answer is never wrong, but always indicates what you feel comes closest to reality. Do not think too long about an answer; the first answer that comes to mind is usually the best one. Try to reach agreement on the questions on which you and your colleague have different opinions.

Never = never, Rarely = no more than once a week, Sometimes = a few times a week, Frequently = almost daily

1	Is cheerful	Never 0	Rarely 1	Sometimes 2	Frequently 3	B
2	Makes restless movements	Never 3	Rarely 2	Sometimes 1	Frequently 0	D
3	Has contact with other residents	Never 0	Rarely 1	Sometimes 2	Frequently 3	F
4	Rejects help from nursing assistants	Never 3	Rarely 2	Sometimes 1	Frequently 0	A
5	Radiates satisfaction	Never 0	Rarely 1	Sometimes 2	Frequently 3	B
6	Makes an anxious impression	Never 3	Rarely 2	Sometimes 1	Frequently 0	C
7	Is angry	Never 3	Rarely 2	Sometimes 1	Frequently 0	A

8	Is capable of enjoying things in daily life	Never 0	Rarely 1	Sometimes 2	Frequently 3	B
9	Does not want to eat	Never 3	Rarely 2	Sometimes 1	Frequently 0	J
10	Is in a good mood	Never 0	Rarely 1	Sometimes 2	Frequently 3	B
11	Is sad	Never 3	Rarely 2	Sometimes 1	Frequently 0	C
12	Responds positively when approached	Never 0	Rarely 1	Sometimes 2	Frequently 3	F
13	Indicates that he or she is bored	Never 3	Rarely 2	Sometimes 1	Frequently 0	H
14	Has conflicts with nursing assistants	Never 3	Rarely 2	Sometimes 1	Frequently 0	A
15	Enjoys meals	Never 0	Rarely 1	Sometimes 2	Frequently 3	J
16	Is rejected by other residents	Never 3	Rarely 2	Sometimes 1	Frequently 0	G
17	Accuses others	Never 3	Rarely 2	Sometimes 1	Frequently 0	A
18	Takes care of other residents	Never 0	Rarely 1	Sometimes 2	Frequently 3	F
19	Is restless	Never 3	Rarely 2	Sometimes 1	Frequently 0	D
20	Openly rejects contact with others	Never 3	Rarely 2	Sometimes 1	Frequently 0	G
21	Has a smile around the mouth	Never 0	Rarely 1	Sometimes 2	Frequently 3	B
22	Has tense body language	Never 3	Rarely 2	Sometimes 1	Frequently 0	D
23	Cries	Never 3	Rarely 2	Sometimes 1	Frequently 0	C
24	Appreciates help he or she receives	Never 0	Rarely 1	Sometimes 2	Frequently 3	A
25	Cuts himself/herself off from environment	Never 3	Rarely 2	Sometimes 1	Frequently 0	F
26	Finds things to do without help from others	Never 0	Rarely 1	Sometimes 2	Frequently 3	I
27	Indicates he or she would like more help	Never 3	Rarely 2	Sometimes 1	Frequently 0	E
28	Indicates feeling locked up	Never 3	Rarely 2	Sometimes 1	Frequently 0	H
29	Is on friendly terms with one or more residents	Never 0	Rarely 1	Sometimes 2	Frequently 3	F

30	Likes to lie down (in bed)	Never 3	Rarely 2	Sometimes 1	Frequently 0	J
31	Accepts help	Never 0	Rarely 1	Sometimes 2	Frequently 3	A
32	Calls out	Never 3	Rarely 2	Sometimes 1	Frequently 0	G
33	Criticizes the daily routine	Never 3	Rarely 2	Sometimes 1	Frequently 0	A
34	Feels at ease in the company of others	Never 0	Rarely 1	Sometimes 2	Frequently 3	F
35	Indicates not being able to do anything	Never 3	Rarely 2	Sometimes 1	Frequently 0	E
36	Feels at home on the ward	Never 0	Rarely 1	Sometimes 2	Frequently 3	H
37	Indicates feeling worthless	Never 3	Rarely 2	Sometimes 1	Frequently 0	E
38	Enjoys helping with chores on the ward	Never 0	Rarely 1	Sometimes 2	Frequently 3	I
39	Wants to get off the ward	Never 3	Rarely 2	Sometimes 1	Frequently 0	H
40	Mood can be influenced in positive sense	Never 0	Rarely 1	Sometimes 2	Frequently 3	B

Score calculation: in the last column the subscale is mentioned. Summate the scores for each subscale.

Subscale (number of items)	Range	Score	
A: Care relationship (7)	0 – 21	A	
B: Positive Affect (6)	0 – 18	B	
C: Negative Affect (3)	0 – 9	C	
D: Restless tense behavior (3)	0 – 9	D	
E: Positive self-image (3)	0 – 9	E	
F: Social Relations (6)	0 – 18	F	
G: Social Isolation (3)	0 – 9	G	
H: Feeling at home (4)	0 – 12	H	
I: Having something to do (2)	0 – 6	I	
J: Remaining items to be used in future research			

Summary

The number of people with dementia is expected to increase considerably worldwide. Although a large number of people with dementia receive care at home, in the later stages of dementia this is often no longer possible anymore and moving to a long-term institutional care setting is ultimately inevitable for many patients. The expected growth in demand for institutional care and the criticism of the largely medical and nursing-based approach of traditional care homes have resulted in several changes in long-term institutional dementia care. Long-term care facilities for people with dementia are increasingly transforming into small-scale living facilities, in which the guiding philosophy is based on a home-like and person-centred approach. Although it is assumed that living in a small-scale living facility is beneficial both for residents with dementia and their family members, and that working in such facilities is also beneficial for professionals, the evidence for these assumptions is rather scarce.

To contribute to the existing body of knowledge, our study compared a number of small-scale and traditional dementia care facilities in the Netherlands and Belgium, incorporating different aspects of the perspectives of residents, family caregivers and professional caregivers. The perspectives of the different actors in the two countries provide a broader view of the issues studied. The central research question of this thesis is introduced in **Chapter 1**:

‘What are the differences and similarities between small-scale and traditional long-term care settings in the Netherlands and Belgium, from the perspectives of the resident with dementia, the family, and the professional caregiver?’

This central research question is translated into five specific research questions which are answered in the subsequent chapters of this thesis. These questions are as follows:

- (1) Which (combination of) changes in elements affect (different dimensions of) the quality of life of elderly residents with dementia in long-term care settings over the course of one year? (*Chapter 2*)
- (2) What are the benefits of traditional and small-scale living facilities on the quality of life of residents with dementia in the Netherlands and Belgium? (*Chapter 3*)
- (3) How do residents with dementia living in small-scale and traditional long-term care settings in the Netherlands and Belgium differ in terms of activities of daily living, behavioural problems, depression, use of restraints, psychotropic medication, social engagement and visiting frequency of relatives? (*Chapter 4*)
- (4) What is the family caregiver perspective in traditional versus small-scale long-term care settings in the Netherlands and Belgium on the interaction between family caregiver and resident, between professional caregiver and resident, and between family caregiver and professional caregiver? (*Chapter 5*)
- (5) Are there any differences in work-related mental health problems and burnout for professional caregivers working in traditional versus small-scale long-term care settings for older persons with dementia in the Netherlands and Belgium? (*Chapter 6*)

Chapter 2 describes the design of a longitudinal, quasi-experimental study among residents with dementia, with three measurement moments (baseline, after six, and after twelve months), conducted in either small-scale or traditional long-term care settings in the Netherlands and Belgium. The conceptual model of the study has been constructed based on literature, to be able to answer the research question: *‘Which (combination of) changes in elements affect (different dimensions of) the quality of life of elderly residents with dementia in long-term care settings over the course of one year?’*. In the model, the main outcome measure for residents is quality of life. Relevant elements that were found to influence quality of life in long-term care settings were also incorporated in the model; environmental characteristics (country, type of unit, group size and nursing staff); basic personal characteristics (age, sex, cognitive decline, weight and activities of daily living); behavioural characteristics (behavioural problems and depression); behavioural interventions (use of restraints and use of psychotropic medication); and social interaction (social engagement and visiting frequency of relatives). Validated instruments, suitable for residents with dementia, were selected to assess the elements in the model.

Chapter 3 examines the research question: *‘What are the benefits of traditional and small-scale living facilities on the quality of life of residents with dementia in the Netherlands and Belgium?’* Following the design of the main study described in chapter 2, the study was conducted in five long-term care organizations in the Netherlands and Belgium, comprising four traditional and 12 small-scale living units. The data were obtained by nurses and nursing assistants using validated observational measurement instruments. Quality of life was measured using the QUALIDEM, which incorporates nine different quality of life domains. The results showed that in the Dutch sample, residents with dementia in small-scale settings achieved higher mean scores on the quality of life domains ‘social relations’, ‘positive affect’, and ‘having something to do’ than residents in traditional settings. In addition, the mean scores on the domains ‘caregiver relation’ and ‘negative affect’ remained stable over time among residents in small-scale settings, but decreased in traditional settings. Mean scores on the domains ‘positive affect’, and ‘social relations’ decreased over time in small-scale settings, whereas they remained stable in traditional settings. Despite this, at the end of the one-year observation period, small-scale settings still scored higher. In the Belgian sample, residents with dementia in small-scale settings were reported to experience less ‘negative affect’ than their counterparts in traditional settings, which can be explained by differences in depressive symptoms. Over time, however, residents ‘felt more at home’ in traditional settings, contrary to small-scale settings, that showed no change on this quality of life domain. Moreover, the mean quality of life scores on the domains ‘restless behaviour’, ‘having something to do’ and ‘social relations’ decreased in small-scale settings but remained stable in traditional settings. Both small-scale and traditional settings therefore appeared to have beneficial effects on different domains of quality of life of residents with dementia.

Chapter 4 addresses the research question: *‘How do residents with dementia living in small-scale and traditional long-term care settings in the Netherlands and Belgium differ in terms of activities of daily living, behavioural problems, depression, use of restraints, psychotropic medication, social engagement and visiting frequency of relatives?’* Although quality of life is a very important outcome (see Chapter 3), in this chapter we examined whether residents with dementia living in small-scale and traditional living facilities differ on other relevant outcome aspects, such as functional status, behaviour and social interaction. The data were obtained

using validated observational measurement instruments. The results revealed few differences between residents with dementia in small-scale and traditional settings in the two countries. Residents in small-scale settings in the Netherlands were more socially engaged and better able to perform activities of daily living compared to residents in traditional settings. In Belgium, residents in small-scale settings were also better able to perform activities of daily living and showed fewer depressive symptoms than residents in traditional settings. Over time, activities of daily living decreased in residents of both small-scale and traditional settings in both countries. However, at the final measurement moment small-scale settings still scored higher compared to traditional settings. Social engagement also decreased in both countries among residents with dementia in small-scale settings but remained stable among residents in traditional settings. Additionally, behavioural problems decreased over time in traditional settings in both countries but remained stable in small-scale settings. The use of psychotropic medication increased in small-scale settings in both the Netherlands and Belgium. An increase was seen in the use of restraints, as well as the visiting frequency for the Belgian small-scale settings. The use of restraints and visiting frequency remained stable in the other settings.

Chapter 5 addresses the research question: *‘What is the family caregiver perspective in traditional versus small-scale long-term care settings in the Netherlands and Belgium on the interaction between family caregiver and resident, between professional caregiver and resident, and between family caregiver and professional caregiver?’* This part of our study focused on family caregivers of the residents with dementia participating in the study. Until now, little has been known about family caregiver perspectives on interactions within the ‘caregiving triangle’: the interaction between family caregiver and resident, between professional caregiver and resident, and between family caregiver and professional caregiver. Family caregivers of the residents with dementia that participated in the main study received a questionnaire containing questions about their interactions with their relative with dementia and with the professional caregiver. Compared to traditional settings, family caregivers of relatives with dementia living in small-scale settings in both countries had more contact with the professional caregivers, were more satisfied with this contact and felt that staff paid more attention to their feelings as family members. They also reported that staff in small-scale settings exhibited better listening skills towards the residents. Furthermore, compared to those in Belgium, family caregivers in both types of setting in the Netherlands perceived staff to be less hurried and more accepting of support from the resident’s family, and felt that staff more often took the resident seriously. In the move towards more person-centred care for residents with dementia, this study indicates the importance of integrating the family perspective.

Chapter 6 takes professional caregivers as the central focus in addressing the research question: *‘Are there any differences in work-related mental health problems and burnout for professional caregivers working in traditional versus small-scale long-term care settings for older persons with dementia in the Netherlands and Belgium?’* Parallel to the part of the study focusing on residents, similarities and differences in burnout and mental health problems for professional caregivers of residents with dementia in small-scale and traditional long-term care settings in the Netherlands and Belgium have been investigated using a longitudinal survey study. A questionnaire was completed by professionals working in the five different care settings included in the main study. The questionnaire contained questions on personal details as well as two validated measurement scales for mental health problems (GHQ-12) and burnout (UBOS-C). Although mental health problems and emotional strain increased significantly

over time in both types of setting and in both countries, overall levels of health problems and burnout were low. Professional caregivers in small-scale living facilities in both countries showed significantly increased levels of emotional strain compared with their counterparts in traditional units. Additionally, two significant differences were found between the Netherlands and Belgium (in both types of setting). In Dutch settings professional caregivers experienced less “depersonalization” and more “personal accomplishment” than those in Belgian settings.

Chapter 7 presents the general discussion of this thesis after summarizing the results of the studies performed. The lack of convincing evidence from our studies and those carried out by others suggests that small-scale living facilities do not necessarily or exclusively provide the best conditions for achieving the most suitable environment for elderly residents.

While small-scale living facilities might offer advantages for residents in some respects, there are also areas where traditional care settings may be beneficial. This implies that we need to extract the best elements from both types of care setting and incorporate them in a differentiated care supply that has a highly demand-based character.

As a final point, to be able to provide the best possible dementia care, attention needs to be focused on residents, with reference to the ‘caregiving triangle, rather than focusing primarily on the scale of institutional care settings.

Samenvatting (Summary in Dutch)

Wereldwijd groeit het aantal mensen met dementie aanzienlijk. Een groot deel van de mensen wordt thuis verzorgd. Neemt de zorgvraag echter toe in de latere stadia van dementie, dan is verhuizing naar een verpleeghuis vaak onvermijdelijk. De verwachte groei in de vraag naar residentiële zorg en de kritiek op de voornamelijk medische benadering die gehanteerd wordt in traditionele verpleeghuizen, hebben geresulteerd in verschillende veranderingen. Traditionele verpleeghuisafdelingen voor ouderen met dementie worden steeds vaker omgevormd tot kleinschalige woonvormen, waarin de leidende filosofie gebaseerd is op een huiselijke en persoonsgerichte benadering.

In de praktijk, is de veronderstelling dat wonen in een dergelijke kleinschalige woonvorm beter is voor zowel de bewoner met dementie als diens familie en dat het werken in deze woonvormen ook voordelen oplevert voor medewerkers. Er is echter nog weinig bewijs voor de positieve effecten die aan kleinschalig wonen worden toegeschreven.

Om bij te kunnen dragen aan de bestaande kennis, is in dit onderzoek een aantal kleinschalige woonvormen en traditionele verpleeghuisafdelingen in Nederland en België vergeleken. In het onderzoek zijn verschillende aspecten van de perspectieven van bewoners, familie en medewerkers meegenomen. De perspectieven van de verschillende actoren in de twee landen bieden een breed beeld van het bestudeerde onderwerp. De centrale onderzoeksvraag van dit proefschrift is geïntroduceerd in **Hoofdstuk 1**:

‘Wat zijn de verschillen en overeenkomsten tussen kleinschalige woonvormen en traditionele verpleeghuisafdelingen in Nederland en België, vanuit het perspectief van de bewoners met dementie, de familie en de medewerkers?’

Deze centrale onderzoeksvraag is vertaald in vijf specifieke onderzoeksvragen, welke in de op-eenvolgende hoofdstukken van dit proefschrift worden beantwoord. De vragen zijn als volgt:

- (1) Welke (combinatie van) veranderingen in elementen hebben effect op (verschillende dimensies van) de kwaliteit van leven van oudere bewoners met dementie in verpleeghuizen in de loop van een jaar? (*Hoofdstuk 2*)
- (2) Wat zijn de voordelen van kleinschalige woonvormen en traditionele verpleeghuisafdelingen op de kwaliteit van leven van bewoners met dementie in Nederland en België? (*Hoofdstuk 3*)
- (3) Hoe verschillen bewoners met dementie in kleinschalige woonvormen en op traditionele verpleeghuisafdelingen in Nederland en België op het gebied van activiteiten van het dagelijks leven, gedragsproblemen, depressie, gebruik van vrijheidsbeperkende maatregelen, medicatie, sociale betrokkenheid en bezoek van familie? (*Hoofdstuk 4*)
- (4) Wat is het perspectief van de familie in kleinschalige woonvormen versus traditionele verpleeghuisafdelingen in Nederland en België op de interactie tussen de familie en de bewoner, tussen de medewerker en de bewoner, en tussen de familie en de medewerker? (*Hoofdstuk 5*)
- (5) Zijn er verschillen in mentale gezondheidsproblemen en burn-out van medewerkers in kleinschalige woonvormen of op traditionele verpleeghuisafdelingen voor oudere mensen met dementie in Nederland en België? (*Hoofdstuk 6*)

Hoofdstuk 2 beschrijft het ontwerp van een longitudinale, quasi-experimentele studie onder bewoners met dementie, met drie meetmomenten (baseline, na zes, en na twaalf maanden), uitgevoerd in kleinschalige woonvormen en traditionele verpleeghuisafdelingen in Nederland en België. Het conceptueel model van de studie is ontwikkeld op basis van literatuur om de onderzoeksvraag te kunnen beantwoorden: *‘Welke (combinatie van) veranderingen in elementen hebben effect op (verschillende dimensies van) de kwaliteit van leven van oudere bewoners met dementie in verpleeghuizen in de loop van een jaar?’*. De belangrijkste uitkomstmaat voor bewoners in dit model is kwaliteit van leven. Relevante elementen die volgens de literatuur invloed hebben op kwaliteit van leven van ouderen met dementie in verpleeghuizen, zijn ook opgenomen in het model: kenmerken van de omgeving (land, type afdeling, groeps-grootte en personeel), basis persoonskenmerken (leeftijd, geslacht, cognitieve beperking, gewicht en activiteiten van het dagelijks leven), gedragskenmerken (gedragsproblemen en depressie), gedragsinterventies (gebruik van vrijheidsbeperkende maatregelen en gebruik van medicatie) en sociale interactie (sociale betrokkenheid en bezoek van familie). Er zijn gevalideerde meetinstrumenten geselecteerd, toepasbaar bij ouderen met dementie.

Hoofdstuk 3 beantwoordt de onderzoeksvraag: *‘Wat zijn de voordelen van kleinschalige woonvormen en traditionele verpleeghuisafdelingen op de kwaliteit van leven van bewoners met dementie in Nederland en België?’* In navolging van het design van de hoofdstudie, beschreven in hoofdstuk 2, is deze studie uitgevoerd in vijf organisaties voor verpleeghuiszorg in Nederland en België. Daarbinnen zijn vier traditionele verpleeghuisafdelingen en twaalf kleinschalige woonvormen onderzocht. Gegevens zijn verzameld met behulp van gevalideerde meetinstrumenten. Verzorgenden en verpleegkundigen vulden deze op basis van observatie in. Negen domeinen van kwaliteit van leven zijn gemeten met de QUALIDEM. De resultaten laten zien dat bewoners in de Nederlandse onderzoeksgroep in kleinschalige woonvormen, hogere gemiddelde scores hadden op de kwaliteit van leven, domeinen ‘sociale relaties’, ‘positief affect’, en ‘iets om handen hebben’ dan bewoners van traditionele verpleeghuisafdelingen. De gemiddelde scores op de kwaliteit van leven, domeinen ‘zorgrelatie’ en ‘negatief affect’, bleven stabiel gedurende het jaar onder bewoners in kleinschalige woonvormen, maar namen af op traditionele verpleeghuisafdelingen. Gemiddelde scores op de kwaliteit van leven, domeinen ‘positief affect’ en ‘sociale relaties’, namen af gedurende het jaar in kleinschalige woonvormen, terwijl deze stabiel bleven op traditionele verpleeghuisafdelingen. Desondanks waren de scores in kleinschalige woonvormen aan het einde van het geobserveerde jaar nog steeds hoger dan die op traditionele verpleeghuisafdelingen. Bewoners met dementie in de Belgische onderzoeksgroep hadden in kleinschalige woonvormen minder ‘negatief affect’ dan op traditionele verpleeghuisafdelingen, wat verklaard kan worden door verschillen in depressieve symptomen. Bekeken over de periode van een jaar, namen de scores van bewoners op traditionele verpleeghuisafdelingen op de kwaliteit van leven, domein ‘zich thuis voelen’, toe, in tegenstelling tot kleinschalige woonvormen, waar geen verandering is waargenomen op dit domein. Bovendien namen de gemiddelde kwaliteit van leven scores op de domeinen ‘rusteloos gedrag’, ‘iets om handen hebben’ en ‘sociale relaties’ af in kleinschalige woonvormen, maar bleven deze stabiel op traditionele verpleeghuisafdelingen. In kleinschalige woonvormen ervaren ouderen met dementie voordelige effecten op andere domeinen van kwaliteit van leven, dan op traditionele verpleeghuisafdelingen.

Hoofdstuk 4 behandelt de onderzoeksvraag: *‘Hoe verschillen bewoners met dementie in kleinschalige woonvormen en op traditionele verpleeghuisafdelingen in Nederland en België op het gebied van activiteiten van het dagelijks leven, gedragsproblemen, depressie, gebruik van vrijheidsbeperkende maatregelen, medicatie, sociale betrokkenheid en bezoek van familie?’* Hoewel kwaliteit van leven een belangrijke uitkomstmaat is (zie Hoofdstuk 3), is in dit hoofdstuk onderzocht of oudere bewoners met dementie, wonend in kleinschalige woonvormen en op traditionele verpleeghuisafdelingen, verschillen op het gebied van andere uitkomstmaten, zoals functionele status, gedrag en sociale interactie. Gegevens zijn verzameld met behulp van gevalideerde meetinstrumenten. Verzorgenden en verpleegkundigen vulden deze in op basis van observatie. De resultaten tonen weinig verschillen tussen bewoners met dementie in kleinschalige woonvormen en traditionele verpleeghuisafdelingen in de twee landen. Bewoners in kleinschalige woonvormen in Nederland waren meer sociaal betrokken en beter in staat activiteiten van het dagelijks leven uit te voeren, in vergelijking met bewoners op traditionele verpleeghuisafdelingen. Bewoners in kleinschalige woonvormen in België waren ook beter in staat activiteiten van het dagelijks leven uit te voeren en toonden daarnaast minder depressieve symptomen dan bewoners op traditionele verpleeghuisafdelingen. Gekeken naar het verloop in de tijd, nam de zelfstandigheid in activiteiten van het dagelijks leven af voor bewoners in zowel kleinschalige woonvormen als traditionele verpleeghuisafdelingen in beide landen. Kleinschalige woonvormen scoorden echter op het laatste meetmoment nog steeds hoger dan de traditionele verpleeghuisafdelingen. Sociale betrokkenheid nam ook af in beide landen bij bewoners met dementie in kleinschalige woonvormen, maar bleef stabiel bij bewoners op traditionele verpleeghuisafdelingen. Ook gedragsproblemen namen af gedurende het jaar op traditionele verpleeghuisafdelingen in beide landen, maar deze bleven stabiel in kleinschalige woonvormen. Het gebruik van medicatie nam toe in kleinschalige woonvormen in zowel Nederland als België. Tevens was er een toename van het gebruik van vrijheidsbeperkende maatregelen, evenals in de bezoekfrequentie van familie in de Belgische kleinschalige woonvormen. Het gebruik van vrijheidsbeperkende maatregelen en de bezoekfrequentie van familie bleef echter stabiel op alle andere afdelingen.

Hoofdstuk 5 behandelt de onderzoeksvraag: *‘Wat is het perspectief van de familie in kleinschalige woonvormen versus traditionele verpleeghuisafdelingen in Nederland en België op de interactie tussen de familie en de bewoner, tussen de medewerker en de bewoner, en tussen de familie en de medewerker?’* Dit onderdeel van onze studie richtte zich op de familie van de ouderen met dementie die deelnamen aan het onderzoek. Tot nu toe was er weinig bekend over het perspectief van de familie op de interactie binnen de ‘zorgdriehoek’: de interactie tussen de familie en de bewoner, tussen de medewerker en de bewoner, en tussen de familie en de medewerker. Familie van de bewoners met dementie die deelnamen aan de hoofdstudie ontvingen een vragenlijst over hun interacties met hun familielid met dementie en met de medewerkers van de afdeling. In vergelijking met traditionele verpleeghuisafdelingen, hadden familieleden met een naaste wonend in een kleinschalige woonvorm, meer contact met de medewerkers van de afdeling, waren meer tevreden over dit contact en vonden dat de medewerkers meer rekening hielden met hun eigen gevoelens als familieleden. Ook rapporteerden ze dat medewerkers in kleinschalige woonvormen beter luisterden naar de oudere bewoner met dementie. Daarnaast vond familie in Nederland, in vergelijking met familie in België, dat de medewerkers minder gehaast waren, vaker hulp van familie accepteerden en de bewoner vaker serieus namen. In de beweging naar meer persoonsgerichte zorg voor bewoners met dementie, benadrukt dit onderzoek nog eens het belang van het integreren van het familieperspectief.

Hoofdstuk 6 richt zich op de medewerker door de volgende onderzoeksvraag te beantwoorden: *‘Zijn er verschillen in mentale gezondheidsproblemen en burn-out van medewerkers in kleinschalige woonvormen of op traditionele verpleeghuisafdelingen voor oudere mensen met dementie in Nederland en België?’* Parallel aan de hoofdstudie onder bewoners, zijn de overeenkomsten en verschillen in mentale gezondheidsproblemen en burn-out onderzocht bij medewerkers in kleinschalige woonvormen en op traditionele verpleeghuisafdelingen in Nederland en België, door middel van een longitudinaal vragenlijstonderzoek. Medewerkers, werkzaam in de vijf zorgorganisaties, die ook deelnamen aan de hoofdstudie, vulden op twee meetmomenten (baseline en na twaalf maanden) een vragenlijst in. De vragenlijst omvatte vragen over basis persoonskenmerken, evenals twee gevalideerde meetschalen voor mentale gezondheidsproblemen (GHQ-12) en burn-out (UBOS-C). Hoewel mentale gezondheidsproblemen en emotionele druk in beide type afdelingen en in beide landen toenamen gedurende het jaar, ervaren zij deze problemen nauwelijks. Medewerkers in kleinschalige woonvormen ervaren meer emotionele druk in vergelijking met medewerkers op traditionele verpleeghuisafdelingen. Daarnaast zijn ook twee verschillen tussen landen gevonden (in beide type afdelingen). In de Nederlandse verpleeghuizen ervaren medewerkers minder ‘depersonalisatie’ en meer ‘persoonlijke bekwaamheid’ dan medewerkers in de Belgische verpleeghuizen.

Hoofdstuk 7 vat de resultaten samen en presenteert de algemene discussie van dit proefschrift. Op basis van onze studie en die van anderen kan geconcludeerd worden dat kleinschalige woonvormen niet per definitie de best passende omgeving voor oudere bewoners met dementie zijn.

Hoewel kleinschalige woonvormen voordelen kunnen bieden voor bewoners op bepaalde domeinen, zijn er ook domeinen waarop traditionele verpleeghuisafdelingen gunstige effecten hebben. Daarom is het nodig om de beste elementen uit beide typen woonvormen te kiezen en te combineren in een gedifferentieerd zorgaanbod voor ouderen met dementie.

Ten slotte moet de aandacht niet slechts gericht zijn op de schaal waarop residentiële zorg wordt aangeboden, maar moet de bewoner met dementie, binnen de ‘zorgdriehoek’, in het middelpunt staan, om de best mogelijke dementiezorg te kunnen bieden.

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Meer professionals

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Luuk, jij bent een geweldige man. Je bent innemend en denkt ruimhartig en inclusief. Met je uitstraling weet je mensen en harten voor je te winnen. In ieder geval dat van mij. Je hebt hard gewerkt en hebt met je beide studies mooie resultaten behaald die jou de kans bieden om een prachtige toekomst tegemoet te gaan. Ik hoop dat we nog veel mooie momenten zullen delen.

Otto, wat lijkt jij op je vader! Je springt door het leven. Altijd vol ideeën, energie en altijd weet je de mensen - ook mij - te verrassen. Jij wilt alles uit het leven halen wat mogelijk is en dat lukt je nog ook! Ik heb zelden iemand ontmoet die op zo'n jonge leeftijd zoveel gezien en geleerd heeft van de wereld. Ook jij gaat een prachtige toekomst tegemoet. Ik weet zeker dat het met jou altijd goed komt!

Annemarie, mijn lieve dochter. Jij bent het mooiste geschenk van mijn leven. Je bent een ondernemend en uniek persoon. Ik ben trots op de dromen die je hebt en heb bewondering voor de manier en de overtuiging waarmee jij ze waarmaakt. Je regelde zelf je reis en verblijf voor een jaar in Amerika na de middelbare school. Je voltooide je hbo-opleiding Verpleegkunde en startte met enthousiasme je studie Verpleegwetenschappen met een toekomstblik naar onderzoek en wetenschap. Jouw wereld is zonnig en barstensvol mogelijkheden. Je maakte je eerste stapjes aan mijn hand. Terwijl de jaren voorbijgaan, neem je meer en meer stappen alleen. Onthoud dat mijn hand en mijn hart er altijd voor jou zullen zijn. Ook op deze belangrijke dag voor mij heb je een grote rol op je genomen samen met **Max**, je lieve vriend op wie wij erg gesteld zijn. Er ligt voor jullie samen een mooie toekomst en ik hoop dat ik daar nog vele jaren in mag delen.

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Grant

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Award

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Curriculum Vitae

Alida Hendrika Petronella Maria (Ietje) de Rooij - als oudste kleinkind genoemd naar haar oma - werd geboren op 15 maart 1955 te Den Dolder. Het eerste kind in een gezin van zes.

Na het behalen van het diploma van de Hogere Burger School (HBS A) aan het Titus Brandsma College te Dordrecht, ging ze in 1972 als AFS (American Field Service) exchange student een jaar in Amerika studeren aan de Wicomico Senior Highschool, te Salisbury, Maryland en woonde daar bij de familie Rose. Na het behalen van het high-schooldiploma in 1973 startte zij hetzelfde jaar de opleiding Fysiotherapie aan Hogeschool te Rotterdam. Tijdens deze opleiding was zij werkzaam als helpende in het psychogeriatrisch verpleeghuis Het Parkhuis te Dordrecht en ging een aantal jaren mee als begeleidster van F.O.K. - kampen (Fibrosekinderen Op Kamp). Daarnaast was zij hulptrainer/zweminstructrice van de zwemvereniging Nautilus.

Na het afronden van haar opleiding begon zij als fysiotherapeut te werken in verschillende bejaardenverzorginghuizen in Dordrecht, was fysiotherapeut van de Invalide Sportbond in Dordrecht en medeoprichter en fysiotherapeut van de cursus 'Zwemmen en bewegen voor aanstaande moeders'.

In 1980 werd zij hoofd van de afdeling fysio- en (later) ergotherapie van verpleeghuis De Sterrenlanden te Dordrecht, een gecombineerd somatisch-psychogeriatrisch verpleeghuis en was daar onder meer de voorzitter van de personeelsvereniging, de BOPZ en MIP-commissie en projectleider van de werkgroep Multidisciplinair Samenwerken. Daarnaast was zij secretaris van de landelijke Vereniging voor Hoofden Fysiotherapie (VHF) en voorzitter van het Nederlandse Rode Kruis, afdeling Dordrecht.

In 1990 behaalde zij haar propedeuse Nederlands Recht aan de Erasmus Universiteit te Rotterdam. Na een tussenpose van twee jaar, na het overlijden van haar beste vriendin Truus en daardoor de opvang van de zorg voor haar zoontje Jeroen in gezin Busink, rondde zij deze studie in 1998 af in de privaatrechtelijke variant aan de Open Universiteit van Heerlen met de scriptie 'De BOPZ, een wet over dwang en verzet. Een evaluatie in theorie en praktijk'. Na het behalen van haar diploma werd zij lid van de Klankbordgroep Wet- en regelgeving van de Nederlandse Vereniging voor Verpleeghuiszorg (NVVZ) en ondersteuner van de Centrale Cliëntenraad Drechtsteden / De Grote Rivieren te Dordrecht (in dienst van LPR, Landelijke Patiënten Raden, te Utrecht). Daarnaast was zij in deze tijd secretaris van de Stichting Koopvaardij '40-'45.

In 2000 werd zij locatiemanager van Oosterhof, een verpleeghuis van de Van Neynselstichting in 's-Hertogenbosch en in 2005 directeur van Woonzorgcentrum de Kievitshorst, De Wever. Verder is zij voorzitter van de commissie Wetenschap en Onderzoek en Stuurgroeplid van het UKON (Universitair Kennisnetwerk Ouderenzorg Nijmegen), voorzitter van de Beroepscommissie Registratie van het KNGF (Koninklijk Nederlands Genootschap voor Fysiotherapie) en was zij tot 1 januari 2012 bestuurslid van Hospice De Duinsche Hoeve te Rosmalen.

In januari 2007 startte zij haar promotieonderzoek en rondde dit af in maart 2012. Tijdens deze periode gaf zij lezingen over haar onderzoek in Nederland, België, Engeland en Amerika en won de IPA Poster Award tijdens een internationaal congres te Den Haag in 2010.

In 2012 is ze benoemd als clusterdirecteur van Woonzorgcentra de Heikant / de Kievitshorst en begeleidt sindsdien de nieuwbouw voor WZC de Heikant.

Ietje is getrouwd met Jan de Werd en heeft een dochter Annemarie en schoonzoon Max. Jan heeft drie kinderen, Tessy (woont samen met Erwin), Luuk en Otto. Afgelopen zomer heeft zij de periode van het onderzoek afgesloten met een heerlijke familievakantie in Toscane.

